# Long Term Care Now and the Next Generation

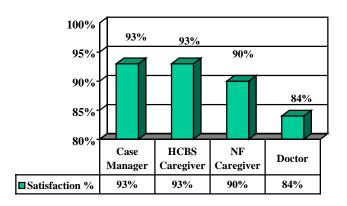


## **EXECUTIVE SUMMARY**

# Q) Is Arizona Taking Care of Long Term Care Business? A) Yes

## CONSUMERS SPEAK OUT

Figure 1: Consumers Overall are Either Very Satisfied or Satisfied with LTC Providers



ALTCS consumers choice of three managed care plans in Maricopa County. As of October 2000, Maricopa long term care consumers have a choice of three long term, managed-care organizations (59% of LTC members reside in this county). Following this change, the Medicaid agency, the Arizona Health Care Cost Containment System (AHCCCS), wanted to take the opportunity to ask current consumers if AHCCCS was taking care of long term care business.

verall, this survey showed that consumers are very satisfied to satisfied with their providers-case manager, doctor, caregiver in HCBS and caregiver in a nursing facility.

## What is the Report About?

Term Care Consumer Long Satisfaction Survey was conducted with 1,031 individuals receiving Medicaid long term care services either in home community-based settings or nursing facilities. The survey measured the elderly and physically disabled members' satisfaction before a consumer had health plan choices. The survey's goals were to: 1) determine what long term care services are important to consumers; 2) assess current satisfaction with the long term care system; and 3) compare satisfaction levels between existing consumers.

## How are we doing?

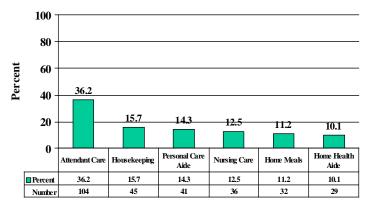


# What Services are Most Important to Consumers?

he ALTCS consumers were asked to speak about the most important service they received and their level of satisfaction with the caregiver.

CBS consumers identified attendant care as the most important service, followed by housekeeping, personal care, nursing care, home meals and home health aide (see Figure 2).

Figure 2: Most Important Services for HCBS Consumers Total Respondents = 287



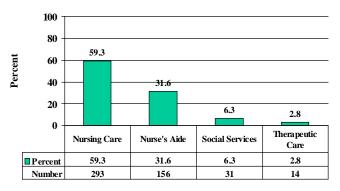
Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents.

"Everything I've ever wanted in terms of home care services is provided to me, I'm very lucky and thankful."

Satisfaction Survey Consumer

ursing facility consumers identified nursing care as the most important service, followed by nurse's aides, social services, and therapeutic care (see Figure 3).

Figure 3: Most Important Services for Consumers in Nursing Facilities Total Respondents = 494



Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents

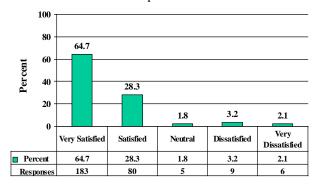


## **CAREGIVERS IN HCBS**

## Consumers and proxies were 93% very satisfied/satisfied with their HCBS caregiver

The evaluation of HCBS care by consumer or proxy was based on the service the consumer was receiving and believed to be most important (see Figure 4). The graph below shows the overall satisfaction levels consumers had for their most important caregiver. The consumer was asked to rate the provider in five areas: shows respect, provides help, listens to consumer, involves consumer, and is reachable.

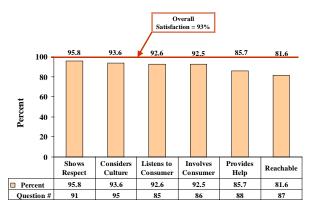
Figure 4: Overall Satisfaction with HCBS Care giver Total Responses = 283



Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents

Consumers showed that they are very satisfied to satisfied with their most important caregiver. The percentages range from 95.8% (shows respect) to 81.6% (is reachable).

Figure 5: Consumers Who are Very Satisfied or Satisfied with HCBS Care giver

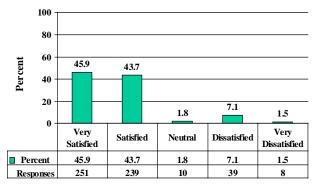


## **CAREGIVERS IN NF**

## Consumers and proxies were 90% very satisfied/satisfied with their NF caregiver

The consumers evaluation of the nursing facility caregiver was based on the NF service the consumer was receiving and believed to be most important (see Figure 6). The graph below shows the overall satisfaction levels for consumers with their NF caregiver.

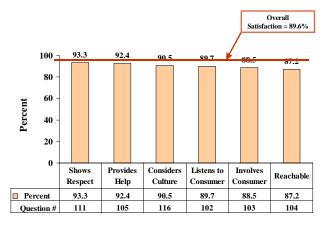
Figure 6: Overall Satisfaction with NF Care giver Total Responses = 547



Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents

The consumers showed they were very satisfied to satisfied with their nursing facility caregiver. The percentages ranged from 93.3% (shows respect) to 87.2% (is reachable).

Figure 7: Consumers Who are Very Satisfied or Satisfied with NF Care giver



## CASE MANAGER

Consumers and proxies were 93% very satisfied/satisfied with their case manager

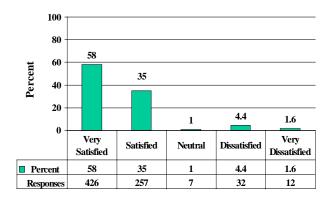
he survey shows that the majority of the consumers were very satisfied or satisfied with their case manager (see Figure 8).

n addition, 74% of respondents knew their case manager. Respondents in the nursing facility were less likely (61%) to know their case manager than those in the home (88%). With 26% of the respondents not knowing their case managers, the question is, "Why"? Were these responses a result of the consumer:

- Not recognizing the term "case manager;"
- Not knowing them; or
- Another reason?

This issue will be further explored in a later study.

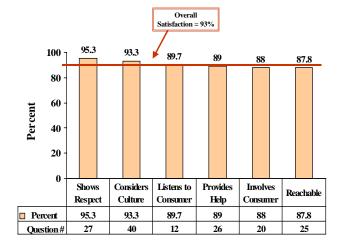
Figure 8: Overall Satisfaction with Case Manager Total Responses = 734



Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents

onsumers rated case managers in five key areas (see Figure 9) with results ranging from a high satisfaction rate of 95% for case managers who show respect to 87.8% for case managers who are reachable.

Figure 9: Consumers Who are Satisfied or Very Satisfied with Case Managers



"All the case managers I've had experience with have been excellent."

Satisfaction Survey Consumer

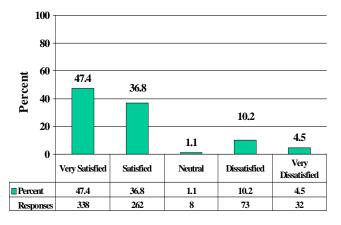


## **DOCTOR**

## Consumers and proxies were 84% very satisfied/satisfied with their AHCCCS doctor

ll respondents were asked if they knew their doctor. Seventy-four percent did. NF respondents were less likely to know their doctor (62%) than those living at home (86%). In addition, the consumer respondents (86%) were more likely to know their doctor than proxies (70%).

Figure 10: Overall Satisfaction with AHCCCS Doctor Total Respondents = 713

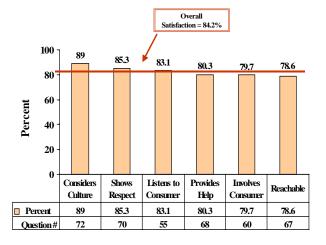


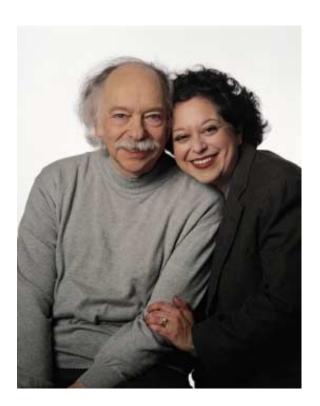
Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents.



onsumers rated their doctors in five key areas. The results indicate the highest rating showing respect (85.3%) and the lowest rating was the doctor being available for consumers.

Figure 11: Consumers Who are Very Satisfied or Satisfied with AHCCCS Doctors





## **What Other Aspects Affect Consumer Satisfaction?**

o determine if there are differences in the way consumers responded to the survey, analyses were conducted based on the following groupings:

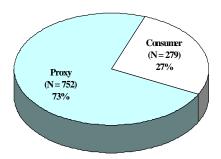
- Proxy vs. consumer,
- Placement (HCBS or NF), and
- Ages (18-64 or 65+).

### PROXY VS. CONSUMER

s previously indicated, there was a total of 1,031 respondents to the survey. A total of 752 (73%) were proxy respondents and 279 (27%) were consumer respondents (see Figure 12).

Figure 12: Is Respondent the Consumer or a Proxy?

Total Respondents = 1,031

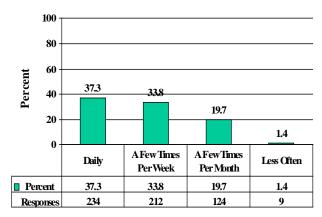


o determine if the proxy-versusconsumer grouping affected the level of satisfaction, researchers analyzed whether an individual was a proxy or a consumer. The following statistical differences were found. Areas that showed statistically significant differences were:

- Consumers were more likely to know their doctor (86%) than proxies (70%).
- Consumers were overall more satisfied with doctors (88%) than the proxies (84%).
- Consumers were more satisfied (92%) with a doctor showing respect than were proxies (83%).
- Consumers were more satisfied (87%) with their doctor involving them than did proxies (81%).

here was a high degree of proxy involvement (see Figure 13). More than 70% of proxy respondents were involved with their consumer either daily or a few times per week.

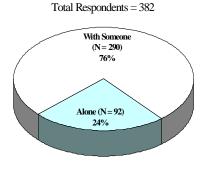
Figure 13: Degree of Proxy Involvement Total Respondents = 579



Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents. There were 752 proxy respondents for the survey.

n addition, the survey shows that most consumers live with someone or have family near by.

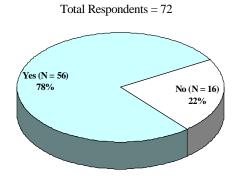
Figure 14: Consumer Lives Alone or With Someone



Note: Not all questions were answered by all respondents.

he results indicate that proxies can provide meaningful information to Arizona's long term care system. In addition, this survey clearly shows that proxies are important caregivers in many situations as well as consumers of long term care services for their family or friends.

Figure 15: Consumer Has Family and/or Friends Near



Note: Not all questions were answered by all respondents

## BY PLACEMENT

o determine if the consumer's place of residence (referred to as placement) affected the level of satisfaction, an analysis was conducted between those consumers who lived in home and community-based settings and those who lived in a nursing facility. The following statistical differences were found in the home and community-based setting versus the nursing facility setting.

HCBS consumers compared to NF consumers were more satisfied with:

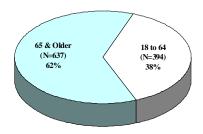
- ➤ Knowing their case manager (88%) to (61%).
- > Case manager listening skills (94%) to (91%).

- Case manager providing help (91%) to (84%).
- ➤ Case manager involving them in decision-making (94%) to (91%).
- ➤ Overall satisfaction of their doctor (90%) to (79%).
- > Doctors providing help (85%) to (74%).
- ➤ Doctor's listening skills (90%) to (79%).
- Doctors involving them in decision-making (91%) to (72%).
- Doctor being very easy to easy to reach (68%) to (61%).
- ➤ Doctor respecting them (94%) to (81%).

## **BY AGE**

o determine if age affected the level of satisfaction, an analysis was conducted between two age groups.

Figure 16: Distribution of Age Among All 1,031 Respondents

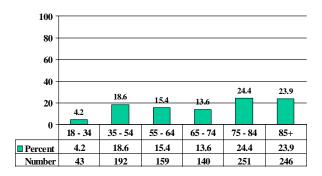


Men Age = 69.6 Years

he following statistical differences were found between those consumers in the 18-64 age group vs. those consumers in the 65+ age group. Consumers who were 18-64 years of age were overall less satisfied with the case managers.

- > Overall (91%) to (96%).
- > Involving them in decision-making (90%) to (95%).
- ➤ Reachability (88%) to (93%).
- > Showing respect (93%) to (98%).

Figure 17: Distribution of Age Groups Among All 1,031 Respondents



# Do Consumers Want Health Plan Choices?

## A? B? C?

everal weeks before this survey began, ALTCS consumers in Maricopa County received information regarding a first-time opportunity to choose among health plans for their long term care services.

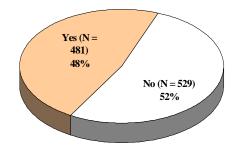
participating in the pre-choice satisfaction survey were interested in receiving more health plan choice. The post-choice survey in the fall of 2001 will look at why or why not consumers or proxies changed health plans. The survey will also assess if satisfaction levels changed.

# Do Consumers Know How to Register a Complaint?

easuring consumers' knowledge about how and where to file a complaint was an important step in assessing satisfaction with long term care providers and services. Forty-eight percent of respondents indicated they know how to contact Maricopa Long Term Care about complaints (see Figure 18).

f those who filed a complaint, 99.2%, indicated they were very satisfied to satisfied that the complaint was handled fairly.

Figure 18: Consumer Knows How to Contact Maricopa County Long Term Care About Complaints After Seeking Help from Case Manager Total Respondents = 1,010



Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents.

## What are the Policy Issues?

### CONCLUSION

he results of the focus groups and the Long Term Care Consumer Satisfaction Survey were compiled into four policy issues to guide state leaders as they reform the long term care system in general and improve ALTCS in particular. In late 2001, the research team will re-interview the initial respondents by telephone with the same survey tool. Data will be compared to the current consumer survey, which will function as the base line tool. At that time, a comparison report of the new findings will be shared with the community.

# How can AHCCCS Promote the Broader Choices of ALTCS Services?

I t is clear from the survey that consumers are more satisfied with home and community-based care than with nursing facilities, although satisfaction in both settings is high. Consumers also want to participate more closely in directing their care.

#### **Policy Issue:**

The state has the opportunity to (1) tell consumers and family members that "long term care" no longer means the only option is a nursing facility; (2) re-evaluate how money is allocated for long term care to encourage more home and community-based services; (3) give providers more information about choices and consumer needs; and (4) redefine which home and community-based settings and services can be offered to both the member and the caregiver.

# Do Consumers Really Want to choose their Health Plan?

or the first time, AHCCCS is offering ALTCS members a choice of managed care organizations to serve them, starting with Maricopa County in 2000 and the rest of the state in 2001. The project's survey of ALTCS members came about largely because of this opportunity to choose. Survey respondents underscored this change by emphasizing they wanted to choose who served them.

#### **Policy Issue:**

These surveys are giving the state the chance to see why people choose a health care plan, and why this choice is important to them. A future survey and report will give better direction to establish the best benchmarks for improving care.

# How can Consumers and Proxies Continue to Give their Valuable Input?

here is no question that input from ALTCS consumers is important to help identify which public policy issues should be tackled first.

#### **Policy Issue:**

➤ To continue receiving consumer input, state policy makers should (1) develop a survey center that can be used by long term care contractors, health plans and state agencies that deal with long term care and aging services; (2) share the cost of operating this center among long term care contractors, health plans and state agencies; (3) standardize the way surveys are worded and conducted so there is comparable feedback; and (4) develop a strategic plan to address issues gleaned from continuing input.

# How Did the Maricopa County Long Term Care Plan Rate?

verall, very well. Consumers were either satisfied or very satisfied with their doctors, case managers and caregivers in either home and community-based settings or nursing facilities. However, the ease with which doctors, caregivers or case managers could be reached received lower ratings.

#### **Policy Issue:**

- ➤ Show doctors, caregivers and case managers how they can be more available.
- ➤ Help doctors become more involved in the consumer's long term care services. Specifically, doctors should include the consumer or proxy in more decision-making, listen more, be more accessible, be more respectful and provide more help.

#### **SUMMARY**

inally, this project has helped determine whether choice among consumers is an important consideration. It is, but we need a better understanding of why individuals want this choice.

Il participants in this research clearly wanted a comprehensive approach to deal with an increasing demand on long term care services in Arizona. It has been the intent of this project's working group to help this come about by defining the issues and proposing viable options for policy makers.

10

#### **TABLE OF CONTENTS**

#### **EXECUTIVE SUMMARY**

#### I. PROJECT DESIGN

- A. BACKGROUND
  - AHCCCS LTC PROGRAM
  - GROWTH AND CHALLENGES
  - FUTURE DEMOGRAPHIC CHANGES
  - GENERAL POPULATION
  - ALTCS MANAGED CARE ENVIRONMENT
  - CONSUMER SATISFACTION
- B. PROJECT GOALS
- C. PROJECT PHASES
- **D.** STEERING COMMITTEE
- E. NATIONAL ADVISORY PANEL

#### II. SURVEY DEVELOPMENT

- A. FINDINGS FROM LITERATURE REVIEW
- B. Instrument Development
- C. Pre-testing of Survey Instrument Focus Group
- D. SPANISH VERSION OF TOOL
- E. PRE-TESTING PHASE

#### III. SURVEY IMPLEMENTATION

- A. TRAINING OF INTERVIEWERS
- B. ESTABLISH PROCEDURES
- C. FIRST 100 RESPONDENTS

#### **TABLE OF CONTENTS**

- D. METHOD OF RESEARCHING INCORRECT PHONE DATA
- E. CRITERIA FOR PROXIES
- F. MONITORING INTERVIEWERS AND PHONE INTERVIEW PROCESS

#### IV. METHODS

- A. SURVEY RESPONDENTS
- B. MEASURES
- C. SAMPLE METHODOLOGY
- D. SAMPLE SIZE FOR PHASE TWO
- E. RESEARCH QUESTIONS
- F. ANALYSIS PLAN

#### V. DEMOGRAPHICS AND SAMPLING

- A. ELIGIBLE POPULATION
- B. AGE / PLACEMENT
- C. GENDER
- D. RACE / ETHNICITY
- E. CHARACTERISTICS OF ELIGIBLE POPULATION AND RESPONDENTS
- F. CHARACTERISTICS BY RESPONDENTS AND NON-RESPONDENTS

# VI. GENERAL CHARACTERISTICS AND FINDINGS BY TYPE OF RESPONDENT AND HEALTH STATUS

A. CONSUMER AND PROXY INVOLVEMENT

#### **TABLE OF CONTENTS**

- B. HEALTH STATUS
- C. HCBS vs. Nursing Facility

#### VII. RESULTS OF THE CONSUMER SATISFACTION SURVEY

- A. SATISFACTION WITH CASE MANAGER
- B. SATISFACTION WITH DOCTOR
- C. SATISFACTION WITH CAREGIVER IN HCBS ENVIRONMENT
  - OVERALL SATISFACTION
  - LISTENING
  - DECISION MAKING INVOLVEMENT
  - REACHABILITY
  - Provides Needed Help
  - SHOWS RESPECT
  - CULTURAL NEEDS

# D. SATISFACTION WITH CAREGIVER IN NURSING FACILITY ENVIRONMENT

- OVERALL SATISFACTION
- LISTENING
- DECISION MAKING INVOLVEMENT
- REACHABILITY
- PROVIDES NEEDED HELP
- SHOWS RESPECT
- CULTURAL NEEDS
- E. COMPLAINTS
- F. HEALTH PLAN CHOICES
- G. CONCLUSION

### **TABLE OF CONTENTS**

#### **APPENDICES**

- APPENDIX A NATIONAL ADVISORY PANEL MEMBERSHIP
- APPENDIX B CONSUMER SATISFACTION SURVEY INSTRUMENT
- APPENDIX C TABLE 1 CHARACTERISTICS OF ELIGIBLE POPULATION VS.

  SURVEY RESPONDENTS
  - TABLE 2 CHARACTERISTICS OF RESPONDENTS VS. NON-RESPONDENTS

#### I. PROJECT DESIGN

#### A. BACKGROUND

#### AHCCCS' LTC Program – Arizona Long Term Care System (ALTCS)

Arizona's Health Care Cost Containment System (AHCCCS) was established in 1982 as a comprehensive Title XIX managed care program authorized under a Section 1115 demonstration waiver. In 1987, Arizona passed legislation to include a long term care component known as the Arizona Long Term Care System (ALTCS). There are two populations serviced in this program, Elderly and Physically Disabled (EPD) and The EPD population can be defined as those Developmentally Disabled (DD). individuals who are elderly (over 65 years of age) or those who have a physical disability regardless of age and have been determined to be "at risk" of institutionalization. The DD population includes those individuals with a developmental disability regardless of age that are determined to be "at risk" of institutionalization in an intermediate care facility for the mentally retarded. In addition, those individuals with a psychiatric condition may be included if there is a non-psychiatric condition or developmental disability that by itself or in combination with other medical conditions (including psychiatric) places them "at risk" of institutionalization. The primary reason individuals need long term care is for assistance with activities of daily living, such as eating, bathing, and dressing. The scope of this research project pertains exclusively to the EPD population age 18 and over.

#### **Growth and Challenges**

The EPD long term care population has evolved into a highly diverse group of individuals. Some of the factors that have contributed to the diversity of this population include: the rapid growth in the number of persons over the age of 85; the number of persons 18-64 years of age has increased significantly in the last few years; and the fact that almost half of the ALTCS population currently live in the community rather than in a nursing home. At the time of this study, enrollment for the ALTCS EPD population in Arizona was approximately 17,500 with approximately 54% (9,400) residing in Maricopa County.

#### Future Demographic Changes

Medical technology, drug therapy, healthier lifestyles, are a few of the factors that have lead to an increased lifespan. The frail elderly (85 years of age and older) are the fastest growing segment of the U.S. population. As a retirement mecca, Arizona's frail elderly population is projected to grow by 200% by the year 2010. In the next 20 years, the number of individuals 75 years and older is projected to grow by 75%, from 3.7 million to 6.5 million. In addition to these statistics, the "Baby Boomer" population will begin reaching Medicare age in the next 10 years. As the population ages, their ability to manage everyday activities diminishes and the need for intensive medical management increases dramatically. Nationally, those with disabilities comprise 17% of the

population but account for 47% of medical expenditures (Arizona Community Based Services and Setting Report, October, 2000).

#### **General Population**

According to Arizona's Community Based Services and Setting Report, October, 2000, "In Arizona, the Department of Economic Security projects that the number of citizens 55 or older will increase from about 900,000 in 1995 to more than 2,100,000 by 2020. By 2014, the number of persons 85 or older will double to approximately 149,000 and comprise 14% of the age 65 or older population. Currently, 110,000 non-institutional Arizonans age 65 or older need some type of assistance with mobility or self-care."

#### **ALTCS Managed Care Environment**

Arizona is the first state to competitively bid the Medicaid managed care long term care program on a statewide basis. Arizona's program is unique because the program includes not only a medical services component, but also offers an array of fully integrated long term care services (e.g., home and community-based services, case management, behavioral health and nursing facilities). Care is coordinated and managed by seven EPD program contractors in the state. Currently, at least one managed care organization (commonly referred to in the ALTCS system as a program contractor) operates in each county. As of October 1, 2000, ALTCS members residing in Maricopa County have a choice of three program contractors. In 2001, the rest of the state will be competitively bid. ALTCS consumers are enrolled with the program contractor in their county of residence.

With the rewriting of A.R.S. § 36-2940, AHCCCS competitively bid for and was awarded three EPD contracts to provide long term care services for the ALTCS EPD program in Maricopa County. The competitive bid process resulted in a choice of three program contractor awards in Maricopa County. Every new applicant and all the existing consumers in Maricopa County now have a choice of program contractors.

#### Consumer Satisfaction

The purpose of this research was to assist AHCCCS in assessing consumer satisfaction with long term care services in Maricopa County before and after the competitive bid. The post-survey in 2001 will examine and determine the number of existing members who remained with current contractors and those who switched to another provider. Therefore, baseline measures were established using the current study's data from July 2000 to February 2001. Further analysis will be based upon the collection of the post-survey data from July 1, 2001 to September 30, 2001 and a comparison will be made between the baseline measures and the post-measures such as the issues of consumer satisfaction and choice. Because AHCCCS is recognized as an innovative program, there may be national interest in this research. The outcomes of this research project will provide other states and the federal government with important information as policy

makers assess whether to replicate the Arizona model, modify it, or undertake alternative programs.

#### B. PROJECT GOALS

Health Services Advisory Group (HSAG) and AHCCCS used the data collected in this research project to address the following two project goals:

Goal One Determine whether the current array of services is adequate for

present and future needs.

Goal Two Gain a clearer understanding of the needs of this population

through an analysis of AHCCCS consumer's socio-demographic

status.

#### C. PROJECT PHASES

It was determined that three project phases were necessary to achieve the goals and complete the necessary tasks associated with the project. Phase One began in May of 2000 with planning the research project and assigning project staff to applicable duties and tasks. Other key objectives associated with Phase One included: a) designing and conducting the focus groups, b) finalizing the survey instrument, and c) finalizing the study's methodology. Deliverables for this phase of the research project included a written report on the focus groups, the design of the final survey instrument, and quarterly reports to AHCCCS and the Flinn Foundation. Phase One ended in July 2000.

Phase Two of the project began in July 2000 and was completed in February 2001. Phase Two consisted of conducting the baseline survey for ALTCS consumers. Feedback was provided to AHCCCS after the first 100 respondents completed their interviews. Demographics, frequency distributions, and proposed modifications to the telephone interview were summarized and discussed with AHCCCS. Objectives for the pre-survey consisted of: a) programming the computerized phone system with the survey, b) training phone interviewers, c) establishing procedures for interviews and monitoring the interviewers, d) developing criteria for the proxies, e) conducting the survey, and f) analyzing and reporting the findings. Deliverables for this phase of the research project included a report on the first one hundred respondents to the survey and quarterly reports to AHCCCS and the Flinn Foundation.

The third phase of the project begins in February 2001 and ends in September 2001. This phase consists of a re-interviewing the initial respondents by telephone with the survey tool. Data obtained in Phase Three will be compared with the data obtained in the baseline survey (Phase Two). Deliverables will include a comparison report of the findings and quarterly reports to AHCCCS and the Flinn Foundation.

#### D. STEERING COMMITTEE

At the onset of the project, a Steering Committee was created to provide necessary oversight and guidance to AHCCCS and HSAG. The Steering Committee consists of staff from both organizations, in addition to the funding agency Flinn Foundation, and Arizona State University responsible for implementing the telephone survey. Three subcommittees -- Advisory Panel, Research, and Data were also created to provide specific guidance on matters relating to either the research methodology or data collection methods and techniques. The role of the subcommittees is considered central to the overall management of this project considering the tight timeline in which all teams work. Each subcommittee has a chairperson and was composed of representatives from each participating organization.

#### E. NATIONAL ADVISORY PANEL

A National Advisory Panel was assembled to work with the Steering Committee. Members of the panel were selected by the Flinn Foundation and AHCCCS and is composed of experts in the fields of long term care, gerontology, sociology, and survey design and implementation. At key stages of the project, the National Advisory Panel provided advice and/or assistance to the various subcommittees, with emphasis in working with the Research Subcommittee. The major duties associated with appointment to this Advisory Panel included review of the survey instrument, review of the research methodology used in the "Baby Boomer" focus group, review of the interim survey result report, and review of the final (2002) survey result report. For a more complete description of the members of the National Advisory Panel, please see Appendix A.

#### II. SURVEY DEVELOPMENT

#### A. FINDINGS FROM LITERATURE REVIEW

The intent of the literature review for this project was to provide a synthesis of information available about existing satisfaction surveys pertaining primarily with the aging population, long term care, and consumer satisfaction with health care. A literature review was conducted to assist the Research Team on the design and development of a satisfaction survey tool specific for Arizona's long term care population. Over the years, many studies have attempted to identify factors that promote consumer satisfaction and categorize consumer satisfaction factors in a variety of taxonomies in order to provide a systematic organization of subsequent research. However, a search of the literature to locate studies that used consumer satisfaction surveys primarily for long term care consumers was lacking. (See Book 1 – "LTC: What do the Experts Say?").

Consequently, the research subcommittee relied upon the following sources in the design of their consumer satisfaction survey: the CAHPS 2.0 survey designed by National Committee on Quality Assurance, Maricopa County Long Term Care Nursing Home Client Survey, Department of Economic Security (DES) Non-Medical Home and Community-Based Services Customer Satisfaction Survey of 1999, Patient Satisfaction Questionnaire (PSQ), and original questions created by the Research Team.

#### B. Instrument Development

Development of the survey instrument was done in several phases. The first phase, as indicated previously, was the review of the literature. The next phase included the selection of survey domains by examining applicable sources for these domains from the literature reviewed. As such, AHCCCS and HSAG obtained several long term care surveys used by local agencies in Arizona. These surveys were reviewed and applicable questions or categories were extrapolated and integrated into the survey instrument. (Appendix B contains the survey instrument used in this study. After each survey question is an "identification tag" of which source was used for the given question).

At this point, the LTC Survey was reviewed by the National Advisory Panel. Consultation with experts from the Advisory Panel offered guidance on content clarity and how best to improve the significance of survey questions. The recommendations of the Advisory Panel were incorporated into the LTC Survey, which was then tested on two focus groups.

#### C. PRE-TESTING OF SURVEY INSTRUMENT-FOCUS GROUP

Two focus groups were conducted to test the survey instrument. The first focus group was conducted at a nursing facility. Eight individuals (four proxies and four consumers) participated in this focus group. The second group was conducted with consumers or family members from home and community-based services. Seven individuals participated in this focus group (two proxies and five consumers). A considerable amount of time was invested in planning and recruiting an adequate number of focus group participants in the home and community-based setting in order to ensure a representative sample.

The findings of the focus groups indicted that a number of important issues needed further consideration prior to the instrument being finalized. First, the question pertaining to cultural factors was unclear to most focus group participants and, as such, a culturally related question was adapted from the Acute Care survey used by AHCCCS. Second, residents of nursing facilities, community based individuals or their relatives did not know that there was a telephone number available for addressing problems and complaints. Third, the terminology in which participants referred to AHCCCS, Arizona Long Term Care System (ALTCS), county or Maricopa Long Term Care Plan is very broad and many participants indicated confusion over the terms and what they really meant. It was, therefore, important during the administration of the survey to determine which term the participant associates with, which provision of service they are familiar with, and then use that term throughout the survey. Subsequently, this was adapted throughout the survey and the script used by interviewers. Finally, focus group participants indicated that the survey questions were appropriate, clear, concise, and understandable.

At the conclusion of the focus groups, the Research Subcommittee reviewed the recommendations made by the facilitator and incorporated them into the survey tool. Feedback was also obtained from the Advisory Panel regarding the contents of the tool. In consultation with AHCCCS, recommendations were evaluated and changes made to the survey tool. The finished tool was referred to the Director of AHCCCS and the Flinn Foundation for final review and approval.

#### D. SPANISH VERSION OF TOOL

Before the tool was pretested, it was translated into Spanish by ASU and tested to ensure that the translation from English to Spanish did not change the contextual meaning of any of the questions. The procedure for utilizing the Spanish version of the tool was as follows: When a call was made and the interviewer determined that the consumer or proxy could speak only Spanish, arrangements were made for the interviewer, who was fluent in Spanish, to call the individual back at a later time and conduct the survey using the Spanish version of the tool. This procedure was followed during the pre-test and survey phases.

#### E. PRE-TESTING PHASE

Programming the Computer Assisted Telephone Interview (CATI) with the survey questions, rehearsal of the script by the interviewers and pre-testing of the survey instrument was immediately begun by Arizona State University Survey Research Laboratory (ASU/SRL) following final approval of the survey tool. The CATI instrument was programmed by the ASU/SRL staff and tested. While the CATI instrument was being programmed, the interviewers who had been trained for the project rehearsed with paper copies of the survey script to familiarize themselves with the wording of the questions and the skip pattern of the questions. Once the CATI instrument was programmed, the interviewers practiced using the CATI equipment and the programmed script. Feedback was provided by the SRL Supervisor enhancing interrater reliability.

II - 2

The final activity in the pre-testing phase was to conduct calls on a sample of the study population using the tool. The purpose of this phase was to obtain feedback from the respondents and the interviewers regarding content and sequencing of the questions, phrasing of the questions, length of time needed to complete the entire survey, and the best method of contacting the survey respondents (consumers and proxies).

Data obtained in this phase was to be analyzed after 100 respondents were interviewed and changes made to the survey before it was finalized for use with the remainder of the study population.

The pre-test phase was conducted for two weeks. A total of 328 phone calls were made to consumers and proxies from the study population. Of the calls made, 28 individuals were contacted and interviewed using the survey instrument. At the conclusion of the pretest phase, results were reviewed by the Steering Committee and AHCCCS Administration. Based on data from similar studies, it was believed that the:

- Length of the phone interview should be no longer than 15-20 minutes in length,
- Survey tool needed to re-phrase the cultural question to include aspects of care delivery, and
- Survey tool needed to add a question regarding the overall consumer's perception of the quality of services that they or their family member was receiving.

After reviewing the results, a few changes were made in the wording and sequencing of the questions, so the flow of questions was smoother and the time to administer the telephone survey remained under 20 minutes. The majority of the data obtained during pre-testing, however, related more to how and when to contact respondents (i.e., disconnected or missing phone numbers or no proxy listed and consumer unable to answer questions). As a result of these findings, a procedure was established with Maricopa County Long Term Care Systems for researching erroneous phone numbers and missing proxy information. The procedure, which was developed, was utilized throughout the remainder of the survey.

#### III. SURVEY IMPLEMENTATION

#### A. TRAINING OF INTERVIEWERS

Before interviewers were permitted to conduct telephone interviews for the LTC Consumer Satisfaction Survey Project, they were required to attend a half-day training session on the project. The training session covered the purpose of the project, terminology and definitions commonly used in long term care and Medicaid, advanced interviewing techniques, phone equipment, the survey tool, and required documentation. The majority of the interviewers for this project had previously participated in research projects, utilizing telephone surveys for data collection and possessed good knowledge and skills of phone interviewing techniques.

Administrative staff from the Arizona State University Survey Research Laboratory (ASU/SRL) conducted the training sessions. This enabled the interviewers to become familiar with optimum times to reach respondents.

During the training session, each interviewer was given a manual containing reference materials for the project and general SRL policies and procedures. After the training session, interviewers utilized the manual as a reference guide when questions arose during the interview process. Along with basic AHCCCS terminology, names and phone numbers of key project personnel from AHCCCS, HSAG and ASU were posted in each interviewer's cubicle for easy reference during calls.

Once the interviewer had attended a training session, they conducted "practice" interviews in the laboratory with the phone equipment and the survey script. Administrative staff from ASU/SRL provided verbal feedback to the interviewers during their practice sessions. Upon satisfactory completion of the phone training, interviewers were scheduled to work on the project.

#### B. ESTABLISH PROCEDURES

In order to ensure a systematic approach to handling common issues that interviewers encountered during the project, several procedures were developed. Procedures were developed for issues such as: 1) the number of call attempts; 2) the number of call backs; 3) confidentiality; 4) face-to-face interviews; 5) criteria for proxies; and 6) unavailability of residents at nursing homes. Interviewers were trained on the procedures and laboratory supervisors incorporated the procedures into their monitoring processes.

As the interview process progressed, the researchers found that the face-to-face interview procedure could be eliminated. This was done for three reasons. First the need to eliminate face-to-face interviews centered on the fact that telephone interviews and face-to-face interviews were two separate methodologies. Each methodology affected the individual's response in very different ways and had the potential to skew results. Use of only one methodology was preferred. Second, there was a need to ensure the participation of cognitively alert nursing home residents in the study. To ensure participation, it was believed that face-to-face interviews might be necessary. Because

cognitively alert residents were able to participate in the study by telephone in a quiet and private place within the nursing home, face-to-face interviews were not necessary. And third there were no situations where lack of confidentiality or privacy required face-to-face interviews.

#### C. FIRST 100 RESPONDENTS

The telephone interview process officially began August 5. To strengthen the research design of the study and to ensure that the study questions were properly worded, sequenced and timed, the researchers built into the design a cursory review of results after a minimum of 100 respondents had been interviewed. By August 16, a total of 169 individuals from the study population had been interviewed (28 during the pretest and 141 during the first 11 days of the telephone interview phase). At this point in the study, both quantitative and qualitative data was reviewed by the Research Team. It was determined that the sequence of the questions and the average length of time to complete the survey were satisfactory. However, wording of one question remained a concern.

This question attempted to assess the respondent's satisfaction with the cultural competence of the providers and staff of the Medicaid managed care organization. The results after 100 respondents revealed that the respondents did not appear to understand the question and did not answer it or needed the question repeated several times before they gave a quick answer, signaling the interviewer that they wanted to "move to" the next question. The researchers discussed several ways to rephrase the question to make it more understandable, but decided to keep the original wording, in order to maintain a consistent set of questions for all respondents. The possibility of reformatting this question for Phase Three of the study will be discussed.

#### D. METHOD OF RESEARCHING INCORRECT PHONE DATA

During the pre-testing phase, the issue of incorrect phone data arose. It was determined that some of the phone numbers for consumers and proxies had changed or the condition of the consumer had deteriorated and now a proxy was making decisions on their behalf. Because of these data issues, a procedure was developed with the ASU/SRL Director and the Manager of the Maricopa Long Term Care System (MCLTCS). The procedure required the ASU/SRL Director to send an electronic list weekly to the Manager of the MCLTCS of bad or disconnected phone numbers and incorrect or missing proxy names for consumers who were no longer cognitively intact. Since MCLTCS staff was required to conduct an assessment of their consumers ever 3 months, their database was the most current automated system. Numbers and names were researched by the Manager with the assistance of a staff member from MCLTCS Information System (IS) Department and sent back to ASU within 2-3 working days. If the information provided by MCLTCS IS system was not correct, which occurred a few times, the information was sent back to MCLTCS Manager and she contacted the case manager for the consumer. The case manager typically had the most accurate names and phone numbers for their consumers. This information was communicated to the MCLTCS Manager who sent it to the Director of the ASU/SRL

#### E. CRITERIA FOR PROXIES

As the research design was developed, there was discussion of who would be interviewed for the study, consumer or proxy. The consumer, who was the recipient of LTC services, was the preferred respondent. However, it was known that some of the consumers would be unable to speak for themselves because of physical or psychological conditions. In cases where consumers could not speak for themselves, the Research Team decided that a proxy would be interviewed. In the cases where a consumer had a legal guardian, this individual would be interviewed. The number of consumers with legal guardians was relatively small and very easy to determine. Their family usually provided a significant amount of their care, and frequently spoke on their behalf, because the consumer was cognitively impaired. There were frequent instances where the family member was their parent's caregiver and proxy. In this case, the family member was interviewed as the proxy and the caregiver questions on the survey were skipped. If the interviewer had any concerns about who the proxy was, those cases were referred to MCLTCS for research and follow-up.

The frequency of interactions/ visits between the consumer and the proxy was also an important consideration, because it helped determine how well the proxy knew the consumer and could answer questions about their care. After the pre-testing phase was completed, a question was added to the survey tool, which asked the proxy how often they were involved in health care issues for the consumer. Proxies who had daily interaction with the consumers were more likely to know the current details of the consumer's medical care and were frequently the caregiver. Proxies who had interaction only once per year with the consumer were generally less knowledgeable about the consumer's care and less likely to answer all the survey questions.

#### F. MONITORING INTERVIEWERS AND PHONE INTERVIEW PROCESS

Throughout the phone interview process, an ASU/SRL Administrative staff member was present in the SRL monitoring all interviewers at periodic intervals. A 10% sample of all calls placed by each interviewer was monitored. The interviewer was evaluated using the standardized monitoring form that was used during the initial training session. When the ASU/SRL Administrative staff observed any significant issues, the situation was immediately addressed and the interviewer disciplined, up to and including termination. No serious issues occurred. Minor issues (i.e., modulation of voice) were discussed with the interviewer after the completion of the call, and a periodic follow-up was done to ensure that the issue had been corrected. All monitoring was documented in writing.

Three additional monitoring processes were also instituted. First, monitoring of the phone interview process at the ASU/SRL was conducted weekly by the HSAG Project Manager to ensure a systematic data collection process. Second, staff from AHCCCS also conducted one on-site visit of the ASU/SRL to monitor the telephone interview processes. No significant problems were identified during either of these visits. The third method of monitoring the survey process was through a written status report. The report was developed and sent weekly to the HSAG Project Manager from the ASU/SRL

Director. It summarized the number of interviews conducted and the number of proxies and consumers interviewed.

The ASU Survey Research Laboratory conducted the consumer telephone survey interviews from August 5 through September 30, 2000. ASU conducted daily monitoring of interviewers to ensure collection of required information and provided feedback to the interviewer. Moreover, ASU provided reports detailing the weekly status of interviews for respondents in the home and community based services (HCBS) and nursing facilities (NF). Oversight of the telephone interviews, conducted by ASU, was periodically monitored by HSAG to ensure compliance with established procedures. Phase Three of the project will begin in February 2001 and consist of planning for the one-year follow-up survey that will begin later in 2001.

#### IV. METHODS

#### A. SURVEY RESPONDENTS

The ALTCS enrollment for the EPD population in Maricopa County, as of September 30, 1999, was 9,164. Fifty-six percent (5,139) of these individuals reside in nursing homes. Forty-four percent (4,025) are receiving in home and community-based services. These individuals reside in their own homes, assisted living facilities, assisted living homes or adult foster care homes.

Survey respondents were randomly selected and consisted of EPD individuals age 18 to 64 years and 65 years and older, and enrolled in the ALTCS program. Spouses, family consumers, or legal guardians (referred to as proxies throughout this research report) responded to the survey on behalf of the consumer who suffered from a cognitive impairment. Finally, the group is divided into: 1) those persons residing in home and community-based settings (home, adult foster care, and assisted living), and 2) those persons residing in a nursing facility.

#### B. MEASURES

The survey measured six specific domains: (1) miscellaneous, covering proxy vs. consumers, health status, and HCBS vs. nursing facility; (2) satisfaction with case managers, (3) satisfaction with doctors, (4) satisfaction with caregiver in an HCBS environment, (5) satisfaction with caregiver in a nursing facility environment, and (6) administrative that covered a) how complaints are handled, b) health plan choice, c) improving long term care, and d) do consumers live alone.

To assess self-reported health status of ALTCS survey respondents, two questions from the SF-12 Health Survey were incorporated into the survey. The case manager, doctor, and caregiver items were adapted from CAHPS™, Patient Satisfaction Questionnaire (PSQ), the Non-Medical Home and Community-Based Services Customer Satisfaction Survey 1999, the 1999 MIHS LTC Nursing Home Consumer Survey, the AHCCCS Acute Care Survey, plus the addition of several original questions written by the Research Team. Finally, qualitative data was collected from survey respondents to further describe the perspectives of consumers in measuring satisfaction and dissatisfaction of case managers, doctors, caregivers in both the HCBS and nursing facility environments, and whether choices of health plans was important to consumers.

#### C. SAMPLE METHODOLOGY

AHCCCS provided a database to HSAG with 7,189 consumers who met the eligibility criterion. The eligibility criteria included consumers who were 18 years of age or older, continuously enrolled in the ALTCS program for at least one year with no more than a one month (i.e., 30 days) gap in enrollment, and were currently enrolled in the program.

Two main populations were determined to be of interest to AHCCCS: those consumers in a nursing facility (NF) and those in a home or community based setting (HCBS). These two settings were initially proportionately stratified. Additionally, age groups (i.e., 18-64 and 65+) were utilized for strata.

After meeting with AHCCCS, it was determined that the mortality rate for the ALTCS population was approximately ten percent per year, and the survey was expected to yield a 70 percent response rate. These percentages were developed based on historical data from similar research projects and the research experience of the Data Subcommittee members. It was also decided to use the same individuals for the pre and post-satisfaction (i.e., baseline and follow-up) surveys. Additionally, sampling was to be performed to provide adequate age group representations for comparison.

An initial sample of 1,902 consumers was drawn for the survey using a stratified random sample based on the setting and then the age of the individuals. The eligible population distribution showed 55 percent were in a NF and 45 percent were HCBS. The primary sample strata reflect this proportion. The initial sample of 1,902 was designed to account for mortality and non-response for both the pre and post-satisfaction surveys, with a final sample size of approximately 800 consumers who answered both surveys. Determination of the final sample sizes for all phases of the project was based on standard sampling methodology.

The 65 year and older age group was oversampled due to increased mortality rates. In addition, the age cohort sizes were adjusted because the 18-64 year age group was underrepresented as a result of the oversampling in the older cohort.

After selection of the sample, HSAG sent the data to AHCCCS. Additional fields and current status were then added to the data and returned to HSAG. The status showed that 81 consumers were deceased. Therefore, the sample size was reduced to 1,821 consumers. The table below shows the final sample size for the pre-satisfaction survey sample.

#### D. SAMPLE SIZE FOR PHASE TWO

	18-64	65.	Total
	10-04	65+	Total
NF	405	629	1034
HCBS	314	473	787
Total	719	1,102	1,821

This sample size is expected to yield a final sample size in the post-satisfaction survey of approximately 800 consumers, with approximately 400 consumers in both the NF and HCBS.

#### E. RESEARCH QUESTIONS

The following research questions were identified by the Research Subcommittee as necessary in order to achieve the goals of this research project.

- 1. Is there a difference in how respondents rate their level of satisfaction with case managers, doctors, caregivers based on age or placement grouping?
- 2. Is there a difference in how respondents rate the significance of services in HCBS or nursing facilities based on age group?
- 3. Is there a difference in how consumer and proxy respondents rate the level of satisfaction with case managers, doctors, HCBS and NF caregivers?

#### F. ANALYSIS PLAN

The primary analysis was conducted on the original stratification as specified in the sampling design. Univariate analyses (aggregate level) are presented, as well as by age group and current placement. Descriptive statistics, provided in proportions, were used to determine differences in responses based on age group and current placement. Bivariate analyses for categorical data were computed using the Pearson's Chi Square test. T tests were computed to assess continuous variables.

An underlying question in the study is whether or not (or perhaps to what degree do) proxy responses affect the results. Therefore, responses by proxies were examined and compared to non-proxy respondents. Once again, descriptive statistics, provided in proportions, were to determine if any differences existed between this group. Bivariate analyses for categorical data were computed using the Pearson's Chi Square test.

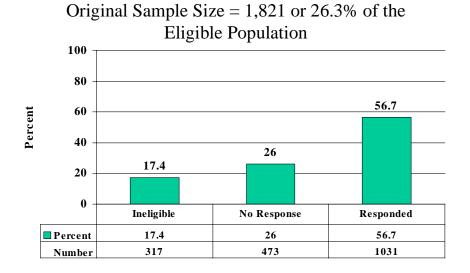
#### V. DEMOGRAPHICS AND SAMPLING

#### A. ELIGIBLE POPULATION

There were a total of 7,189 Maricopa Long Term Care Plan consumers eligible to participate in the survey. Eligibility is defined as being continuously enrolled in ALTCS at least one year and currently still enrolled, with only a one-month gap in enrollment, and at least 18 years of age. Survey respondents were stratified according to placement categories (Home/Community Based Services such as home, assisted living, and adult foster care, and Nursing Facility) and age groups of 18-64 and 65 years of age and older.

The original sample for the survey consisted of 1,821 consumers. A total of 317 consumers were found to be ineligible to participate, 473 did not respond, leaving a final eligible sample size of 1,031 consumers who participated in the survey giving a response rate of 69% (see Figure 1 below).

#### Response Rates



Final Response Rate = 1,031 / (1,821-317 Ineligible) = 68.6%

#### B. AGE/PLACEMENT

There were a total of 1,031 consumers participating in the long term care survey. Fifty-two percent lived in a nursing facility while 48% lived in the home and community. There were 328 respondents who live in the community. Of those living in the community, 24% live alone, while 78% have family or friends who live nearby. The overall mean age was 69.6 years of age, with 62% aged 65 or older. The mean age is lower than anticipated because it was necessary to increase the number of survey respondents in the 18-64 age group so the sample size was large enough to detect for differences. However, when each group is analyzed individually, the mean age in the 18 -64 age group was 50.1 years of age, and the mean age in the 65 years of age and older was 82 years of age, both of which are representative of the ALTCS population.

#### C. GENDER

Literature sources indicate that the majority of individuals receiving long term care through Medicaid are female. Further, 70 percent of caregivers (or proxies) are female. It was important to determine if the statistics for the respondents in the survey were reflective of the statistics in the literature. Of the 1,031 individuals participating in the survey, 65% of the respondents were female. Therefore, gender of the respondents was further analyzed based on whether the respondent was a consumer or a proxy. Data results for this survey did follow national trends in the literature related to gender. Females were represented in greater proportions for both consumers and proxy categories. Consumer respondents were comprised of 55.9% females (n=156) and consumer respondents were comprised of 44.1% males (n=123). Proxy respondents were comprised of 31.4% males (n=236).

#### D. RACE/ETHNICITY

Data was also analyzed according to race/ethnicity in order to determine if the respondents for this survey were similar in composition to the populations cited in the literature review. The majority racial/ethnicity background, for both consumers (77.4%) and proxies (68.8%), was white. Hispanics consisted of ten percent of consumer respondents and fifteen percent of proxy respondents. African Americans consisted of nine percent of consumer respondents and six percent of proxy respondents, while Native Americans consisted of two percent of consumer respondents and one percent of proxy respondents.

#### E. CHARACTERISTICS OF ELIGIBLE POPULATION AND RESPONDENTS

The characteristics between the eligible population and the survey respondents differed significantly only in one area, age. Seventy-six percent of the eligible population was 65 years of age and older compared to 62% of the survey respondents who were 65 years of age and older. (However, on all other characteristics the groups were similar). In regards to placement, the percentage of respondents living in nursing facilities and a HCBS were very similar for both groups, as was the percentage of female caregivers. The average time of enrollment for the eligible population (3.8 years) and the respondents (3.9) years was also nearly identical. (Please refer to the "LTC Survey Data Book," page II-9).

#### F. CHARACTERISTICS OF RESPONDENTS AND NON-RESPONDENTS

The characteristics between respondents versus non-respondents did not differ by much. For example, the total percentage of respondents that were over age 65 was 62%, while non-respondents over age 65 was 59%. The percentage of females was separated only by one percentage point between the groups. There was an 11% difference between those in the nursing facility among respondents (52%) and those among non-respondents (63%). As such, the difference among the groups on HCBS was reversed with respondents living in HCBS at 48% and non-respondents at 37%. Most of the respondents were English speaking. Only 2.5 percent of the respondents had any problem with language. During the interview process, language barriers were addressed. The average time of enrollment was identical. (See "LTC Survey Data Book," page II-9).

# VI. GENERAL CHARACTERISTICS AND FINDINGS BY TYPE OF RESPONDENT AND HEALTH STATUS

The average time to complete a survey by respondents was 20 minutes. According to the interviewers, the majority of all respondents (Consumer and Proxy) understood all or almost all of the questions. Interpreters were available to address language problems and interviewers adjusted phone volume to assist these individuals in completing the survey. Ninety-nine point four percent of all respondents (1,025) stated they would participate in the post-satisfaction survey.

Nearly all of the questions were answered by all of the respondents. Questions about cultural needs were frequently answered as "Does Not Apply." The response "Does Not Apply" was excluded from the analysis so as not to skew the distribution of those who answered the question. Some consumers (or proxies) choose not to answer a particular question. In this instance, the survey is still valid, but the respondent is removed from the denominator for that particular question. Finally, a few questions had too few responses to be meaningful and, therefore, are not presented.

The footnote for each graph may or may not include a reference to a "p-value". This is displayed only when there is a statistical difference between the specified category (e.g., age group or current placement). A p-value that is below 0.05 is considered to be statistically significant. For example, Question 73 concerns Overall Satisfaction with the Doctor and is statistically different (p-value = 0.025) between consumer and proxy respondents. Further analysis reveals that consumers tend to rate the satisfaction with their Doctors somewhat higher than the proxy respondents, yet Question 50 (Do you have one person you think of as your Doctor?) shows that consumers are much more likely to be able to identify their doctor. Therefore, significant p-values should be used as a guide for further investigation.

As previously indicated, the survey measured five specific domains: (1) satisfaction with case managers, (2) satisfaction with doctors, (3) satisfaction with caregiver in an HCBS environment, (4) satisfaction with caregiver in a nursing facility environment, and (5) administrative that covered a) how complaints are handled, b) health plan choice, c) proxy vs. consumer, d) health status, and e) placement. For each of the survey domains, aggregate results are provided, followed by age, consumer/proxy, and current placement categories. The primary scale used throughout the survey was a Likert Scale that ranged from very satisfied to very dissatisfied. It was determined that since this survey was the first AHCCCS satisfaction measure of long term care services it would, thus, serve as the benchmark for ALTCS consumers of long term care services. After reviewing the survey results, a benchmark of satisfied to very satisfied was established.

#### CONSUMER AND PROXY INVOLVEMENT

The total number of consumers participating in the survey was 1,031. Of this total, 279 (27%) were consumers and 752 (73%) were proxies (Figure 1). For purposes of this study, proxies are defined as those individuals who speak on behalf of a consumer who was receiving HCBS or NF services but who was cognitively impaired. Cognitive ability of the consumer was determined in two ways. First, AHCCCS provided confirmation on

the consumer's mental status, as determined by the consumer's case manager during their quarterly client assessment. Second, HCBS and NF caregivers were able to validate the cognitive ability of the consumer, if it had changed since the previous assessment, by reviewing their medical record. The degree to which proxies are involved with a consumer was also measured with the results displayed in Figure 2. As indicated, seventy-one percent of proxy respondents were involved either daily or a few times a week with their family member, friend, or court appointed consumer. The high rate of proxy involvement allowed the Research Team to analyze proxy data with a reassured comfort level regarding how well proxies represented the opinions and perceptions of the consumer.

Consumer
27%
Proxy
73%
Consumer
Proxy

Figure 1. Consumer vs. Proxy Respondents

There was a high degree of proxy involvement. More than 70% of proxy respondents were involved with their consumer either daily or a few times per week.

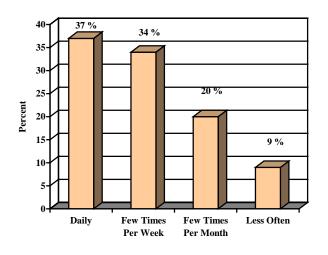


Figure 2. Degree of Proxy Involvement

The results of this survey indicate that the proxies can provide meaningful information to Arizona's long term care system. In addition, this survey clearly shows that proxies are important caregivers in many situations and consumers of long term care services for their family or friends.

#### B. HEALTH STATUS

Irrespective of how the health status of survey respondents was examined, 60% or greater of respondents consistently rated their current general health as fair or poor. Survey respondents who were 65 years of age or older had the highest percentage (68%) of those indicating fair or poor health. The health status of survey respondents was also examined compared to one year ago. Overall, nearly 40% indicated that their health was the same, or somewhat worse (29%). When reviewing this question by age categories, the finding remains the same; that is, nearly 41% indicated that their health was the same, or somewhat worse (23%). However, those in the older age category rated their health compared to one year ago as somewhat worse by 32% and much worse by 11%. When reviewing the question for both respondents in either the home or the nursing facility, the findings again remain quite similar although there is a slight increase in the number of respondents in the nursing facility that indicated their health was much worse. When current health status was analyzed by age category, by consumer vs. proxy and by HCBS vs. NF, all categories were found to be statistically significant at the p = .05 level or greater, indicating variations among the groups (See the "LTC Survey Data Book," Section II).

#### C. HCBS vs. Nursing Facility

Nearly 80% of consumer respondents lived in an alternative residential setting (e.g., adult foster care or assisted living) while only 26% of proxy respondents lived in the home. As expected, 21% of consumer respondents lived in a nursing facility, while 64% of proxies represented consumers living in a nursing facility. This finding is expected given that more consumers in nursing facilities were represented by proxies. The findings in the two age categories were also expected. For example, more consumer respondents were aged 18-64 years of age (62.4%) than proxy respondents (29.3%), while more proxy respondents were aged 65 years of age and older (70.7%) than consumer respondents (37.6%). The gender and race/ethnicity distribution were similar across both consumer and proxy respondents. The gender and race/ethnicity findings eliminated the need to further analyze these variables throughout the survey. Hence, the remaining domains are analyzed according to aggregate, age, consumer/proxy, and current placement categories.

Consumer vs. Proxy Respondents by Placement and Age Grouping

	Consumer	Proxy	Total
	(n=279)	(n=752)	(n=1031)
HCBS	220 (54.8%)	272 (55.2%)	492 (47.7%)
NF	59 (10.9%)	480 (89.1%)	539 (52.3%)
18-64	174 (62.4%)	220 (29.3%)	394 (38.2%)
65 and +	105 (37.6%)	532 (70.7%)*	637 (61.8%)

#### VII. RESULTS OF CONSUMER SATISFACTION SURVEY

The first research question answered in this study was whether or not there was a difference in how respondents rated their level of satisfaction with case managers, doctors, caregivers based on age or placement grouping? A second research question was whether or not there was a difference in how respondents rate the significance of services in HCBS or NF based on age group? A third question was whether or not there was a difference in how consumer and proxy respondents rate the level of satisfaction with case managers, doctors, HCBS and NF caregivers? To answer these questions, survey respondents answered a series of questions to determine the satisfaction ratings of these caregiver groups involved in delivering care and/or services to them. The groups, of course, include case managers, doctors, home and community based caregivers, and nursing facility caregivers.

#### A. SATISFACTION WITH CASE MANAGER

Overall, based on 747 Responses, 74% of respondents knew their case manager. However, 26% of the respondents surveyed do not know their case manager. Respondents in the nursing facility were less likely to know their case manager (61%) than those in the home (88%). A significant difference was found between the two groups. The fact that one quarter of the population surveyed did not know their case manager is important to note because current policy mandates that individuals receiving services in the home and community must receive contact from their case manger every three months, and individuals receiving services in a nursing facility must receive contact from their case manager every six months. It is possible that those respondents indicating they do not know their case manager may only know this individual by name, such as Susan or Katie. As such, the finding that 26% do not know their case manager may be a function of the terminology we are using versus a function of not knowing one's case manager. Further research should be conducted to clarify this finding.

Overall, most respondents indicate that they are very satisfied or satisfied (93%) with their case manager. Overall, respondents in both age categories were quite satisfied with their case managers, with those 65 years of age and older indicating a higher satisfaction rating (96%) than those 18–64 years of age (91%). Regardless of placement setting (home or nursing facility), respondents rated their satisfaction with their case managers very highly (92% or better). This finding remains true irrespective of the age category or the current placement of the consumers.

In addition to the quantitative data collected from the survey, open-ended questions were also asked of respondents, which provided some qualitative data for review. A total of five reasons were highlighted by respondents that led to their satisfaction with case managers. Of importance are three key areas. The first area sited by respondents is case managers are willing to listen and talk with respondents (32%). The second area sited by respondents is case managers are responsive to the needs of consumers (28%). And finally, the third area sited by consumers is case managers care about the consumers.

To further analyze the satisfaction of case managers, a number of key factors were assessed pertaining to the skills and attributes case managers should possess, in order to do ones' job satisfactorily and provide the necessary services for consumers. Most respondents indicate that they are satisfied with their case managers skills in: listening to them, involving them in decision making, reaching them, being helpful and respectful, and being culturally sensitive. Irrespective

of the respondents age category, current placement, or whether they are a consumer or a proxy, respondents are very satisfied with these various attributes displayed by their case managers.

Irrespective of the aggregate or consumer vs. proxy status, the respondent's satisfaction with the case manager's listening skills was consistently greater than 90%. Statistical significance was seen with regard to placement. HCBS consumers were more satisfied (94%) with the case manager's listening skills than NF consumers (91%). The same remains true about case managers involving respondents in decision making. Respondents (consumers and proxies) consistently rated case managers at 87% or above on their listening skills. HCBS consumers were more satisfied (94%) with case managers involving consumers in decision-making than were NF consumers (91%). In addition, consumers 65 years and older were more satisfied that their case manager involved them in decision-making (95%) than consumers 18-64 years old (90%).

Overall, 88% of the respondents considered their case manager easy to reach, with those respondents 65 years of age or older reporting a slightly higher rating of satisfaction (93%). Respondents in the home and nursing facility environment reported similar ratings of satisfaction (90%, 88% respectively).

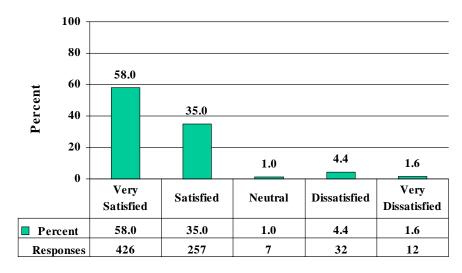
Overall, 89% of all respondents were very satisfied to satisfied that case managers provided the help that they need. Again, those aged 65 years or older reported a higher rating than the overall group or those in the lower age group (92%, 85% respectively). Respondents in the home environment reported that they were very satisfied to satisfied (91%) that case managers are providing help when needed. These results are statistically significant across the satisfaction categories. For respondents who are in the nursing facility environment, they were very satisfied / satisfied (84%) that case managers are providing help when needed. Again, the results are statistically significant across the satisfaction categories.

Overall, 95% of all respondents were very satisfied to satisfied that case managers respected them. Those aged 65 years or older reported a higher rating (98%) than the overall group (95%) or those in the lower age group (93%). Regardless of placement (home or nursing facility) the findings were identical (95%). These results are statistically significant across each of the satisfaction categories and statistically significant between the groups.

A question that caused much confusion among the respondents was the cultural sensitivity question. Although much effort went into the design of this question, the question remained unclear to the respondents and as such 35% of the respondents did not answer the question. Therefore, this question will be re-evaluated prior to the implementation of the post-survey.

The highly satisfied ranking of all case manager categories indicates that case managers are viewed as a highly regarded individual in the long term care system, and that consumers and proxies equally view them as a service that is necessary so consumers can function appropriately given their current medical condition(s) or daily living limitations.

Overall Satisfaction with Case Manager Total Responses = 734

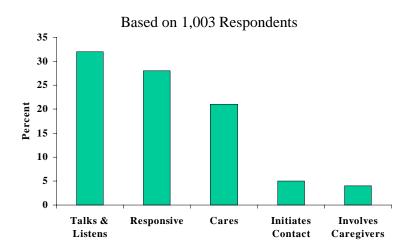


Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents.

# Satisfaction with the Case Manager

No. Question		Very Satisfied		Satisfied		Neutral		Dissatisfied		Very Dissatisfied	
		#	%	#	%	#	%	#	%	#	%
41	Overall Satisfaction with Case Manager	426	58.0	257	35.0	7	1.0	32	4.4	12	1.6
12	Case Manager Listens	408	55.4	275	37.3	9	1.2	33	4.5	12	1.6
20	Case Manager Involves Consumer in Decision Making	344	47.3	296	40.7	34	4.7	33	4.5	20	2.8
25	Case Manager is Reachable	228	43.6	231	44.2	8	1.5	39	7.5	17	3.3
26	Case Manager Provides Needed Help	251	50.2	194	38.8	9	1.8	30	6	16	3.2
27	Case Manager Respects Consumer	486	65.9	217	29.4	7	1.0	24	3.3	4	0.5
40	Case Manager Considers Cultural Needs	150	43.6	171	49.7	8	2.3	14	4.1	1	0.3

What is Main Reason for Satisfaction with Case Managers (Qualitative Question)



Notes: Not all questions were answered by all respondents.

### B. SATISFACTION WITH DOCTOR

Overall, 74% of respondents knew their doctor. A statistically significant response was found between those respondents in the nursing facility and those in the home regarding who knew their AHCCCS doctor (62% vs. 86% respectively). In addition, consumers were more likely to know their AHCCCS doctor (86%) than proxies (70%). It is possible that this finding is because those in the home visit their physicians more frequently than those in the nursing facility. Respondents in the nursing facility have contact with a medical team and a facility physician and, therefore, do not associate with a personal physician. Of those respondents who knew their doctor, 84% were either very satisfied or satisfied with their AHCCCS doctor. There was no difference between the age categories of respondents on how satisfied respondents were regarding satisfaction levels with doctors. However, there was statistical significance between the placement of the respondents and whether they were a consumer or proxy. Consumers were overall more satisfied with their AHCCCS doctors (88%) than proxies (84%). HCBS consumers were overall more satisfied (90%) with their AHCCCS doctors than were NF consumers (79%).

As respondents answered the questions about their satisfaction with specific aspects of their doctor's care, they were asked to only answer these questions if their physician was a doctor employed by AHCCCS. It may be advantageous for AHCCCS to determine the issues centering on nursing facility consumers and their contact with doctors. With nearly 40% of nursing facility respondents reporting that they do not know their doctor, there may be an educational opportunity between doctors and nursing facility consumers.

# Overall Satisfaction with AHCCCS Doctor Total Respondents = 713



Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents.

Overall, 83% of respondents were very satisfied /satisfied that their doctor is listening to them. Overall, respondents in both age categories were quite satisfied with their doctors (82% vs. 84% respectively). There was a significant difference between respondents in the home who were very satisfied that doctors were listening to them (90%) and those respondents in the nursing facilities who were satisfied that their doctors were listening to them (79%). This finding might be attributable to the fact that nursing facility consumers are less likely to know their doctor.

Overall, 85.3% of consumers were very satisfied to satisfied that their doctor respected them. There was no statistical difference for the age categories; however, for consumer vs. proxy status and placement there was statistical significance. Consumers were more satisfied (92%) with a doctor showing respect than were proxies (83%). HCBS consumers were more satisfied (94%) with their doctor respecting them than with NF consumers (81%).

Overall, 80% of respondents were very satisfied to satisfied that their doctor involves them. Overall, respondents in both age categories were satisfied that their doctors involve them (78% vs. 81% respectively). Consumers were more satisfied (87%) with their doctor involving them in decision-making than proxies (81%). Again, respondents in the home were more satisfied (91%) that doctors are involving them than are the respondents in the nursing facility (72%). This finding might also be related to the lower rate of satisfaction among nursing facility respondents when they rate their doctors.

Overall, 79% of respondents considered it easy to reach their doctor. This finding might be lower than expected because the respondents in the nursing facility, represented in this sample by a nearly 2:1 margin, were less likely to know their doctor. There were no differences among age or proxy vs. consumer on this question. Sixty-five percent of respondents in both age categories

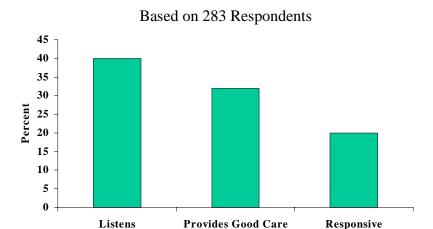
considered their doctor reachable. Again, respondents in the home were more satisfied that doctors are reachable (68%) than the respondents in the nursing facility (61%). Again, this finding might be attributable to the lower rate of satisfaction among nursing facility respondents when they rate their doctors.

#### Satisfaction with the AHCCCS Doctor

No.	o. Question		Very Satisfied		Satisfied		Neutral		Dissatisfied		Very Dissatisfied	
		#	%	#	%	#	%	#	%	#	%	
73	Overall Satisfaction with Doctor	338	47.4	262	36.8	8	1.1	73	10.2	32	4.5	
55	Doctor Listens	337	47.8	249	35.3	15	2.1	65	9.2	39	5.5	
60	Doctor Involves Consumer in Decision Making	298	44.2	239	35.5	22	3.3	72	10.7	43	6.4	
67	Doctor is Reachable	151	45.5	110	33.1	15	4.5	36	10.8	20	6.0	
68	Doctor Provides Needed Help	218	38.4	238	41.9	12	2.1	62	10.9	38	6.7	
70	Doctor Respects Consumer	344	49.9	244	35.4	22	3.2	52	7.6	27	3.9	

In addition to the quantitative data collected from the survey, open-ended questions were also asked of respondents, which provided some qualitative data for review. Based on a sample size of 283, consumers believed that there were three main categories that led to their overall satisfaction with doctors. First, doctors listened to them and were rated as the most important reason for satisfaction for nearly 40% of survey respondents. Second, doctors provide good care to them and was rated as the second most important reason for satisfaction by nearly 35% of survey respondents. Finally, doctors were responsive to them and were rated as the third most important reason for satisfaction for nearly 20% of survey respondents.

# Main Reason for Satisfaction with AHCCCS Doctors (Qualitative Question)



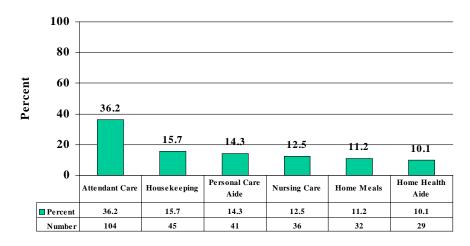
Notes: Not all questions were answered by all respondents.

### C. SATISFACTION WITH CAREGIVERS IN (HCBS) ENVIRONMENT

ALTCS consumers who live in a home environment may receive a variety of services in their home, based on their long term care needs. Several members of the health care team, such as attendants, housekeepers, nurses, and home health aides provide these home-based services. In order to respond to questions about HCBS caregivers, the consumer was first asked to identify which services were most important to them. Respondents were read a list of services available to HCBS consumers and asked that they indicate which service was the most important service to the consumer. There were a total of 287 respondents to this question.

As you review the responses below, keep in mind that the respondent was answering these questions based on which service they indicated was the most important one they received. Three separate analyses were performed for caregivers in the HCBS environment. First, an aggregate, or overall, finding is presented. Second, the findings according to age categories are presented. Third, the findings according to the consumer vs. proxy category are presented.

Most Important Services for HCBS Consumers Total Respondents = 287



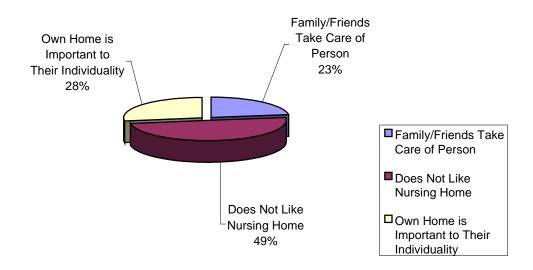
Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents.

#### Satisfaction with Caregiver in HCBS Environment – Overall

Ninety-three percent (93%) of all respondents were very satisfied to satisfied with their HCBS caregiver. The results of the age groups and proxy vs. consumer group are not presented because each category had less than 200 individuals making the sample too small to detect any differences. Although there were no statistical differences in the age groups, an interesting finding is the fact that those consumers aged 18-64 years of age showed a lower rate of satisfaction than those in the 65 and older category. Although the percentage difference is only 5%, this could potentially impact the group as they grow older. Those in the lower age category potentially represent two different populations. First they have the potential to represent a sample with a high rate of disability. Second, the category could also represent a significant number of Baby Boomers. If this group represents the Baby Boomers, then this finding is important to those planning for the influx of Baby Boomers into the system.

Prior to reviewing the analyses conducted on the caregiver within the HCBS environment, the Research Team believes it is important to know the reasons why consumers choose to live at home. Consumers choosing to live at home cited three major reasons for this. First, nearly half of the consumers surveyed (49%) do not like nursing homes and this in and of itself was enough to keep them living at home. Second, 28% of the consumers stated that it was important to maintain your own home. Third, 23% of the consumers cited family and friends as an important factor to their ability to stay at home.

# What is the Reason for Choosing to Live at Home Among HCBS Consumers (n=189)



# Satisfaction with Caregiver in HCBS Environment – Listening

Approximately 93% of consumers were very satisfied to satisfied that the HCBS caregiver listened to their concerns and health care needs. In the two age groups, those 18 to 64 years of age were 92% very satisfied to satisfied that their HCBS caregiver listened to them. Those 65 years of age and older were 93% very satisfied to satisfied that their caregiver listened to them. These findings indicate that caregivers in the HCBS environment demonstrate good listening skills to their consumers.

#### Satisfaction with Caregiver in HCBS Environment – Decision Making Involvement

Ninety-five percent of consumers were very satisfied to satisfied that their HCBS caregiver involved them in their care. Both age groups were equally satisfied with the degree that their caregiver involved them in care. Ages 18-64 years, were 94% very satisfied to satisfied and the 65 years and older age group were very satisfied to satisfied 96% of the time. Though consumers and proxies were satisfied with the caregiver involving them in the consumer's care, proxies displayed a higher percentage of satisfaction than consumers did. Proxies were very satisfied to satisfied 9% compared to 93% for consumers.

#### Satisfaction with Caregiver in HCBS Environment – Reachable

Respondents were asked to rate the satisfaction they had with their ability to reach their HCBS caregiver if they had a question. Ninety-two percent who answered this question were very satisfied to satisfied with their ability to reach their caregiver. Those respondents who were 18 to

64 years of age were 91% very satisfied to satisfied, and those 65 years and older were 93% very satisfied to satisfied with their ability to reach their caregiver. Proxies were more likely to be satisfied than consumers with their ability to reach their HCBS caregiver. Proxies were 95% very satisfied to satisfied and consumers were 90% very satisfied to satisfied. This finding indicates that there is a high rate of satisfaction among both consumers and proxies regardless of age.

# Satisfaction with Caregiver in HCBS Environment – Provides Needed Help

Ninety-four percent were very satisfied to satisfied that their HCBS caregiver provided them with the help they needed. Of those in the 18 to 64 years of age category, 93% were very satisfied to satisfied that their caregiver provided them with needed help, and 95% of those 65 years of age and older were very satisfied to satisfied. Again, proxies were slightly more satisfied 96% than consumers, 93%. This finding indicates, once again, a high level of satisfaction with caregivers in the HCBS environment.

# Satisfaction with Caregiver in HCBS Environment – Shows Respect

Ninety-seven percent of respondents were very satisfied to satisfied with the respect their HCBS caregiver showed them. Both age groups were also very satisfied with the respect their caregiver showed them. In the 18 to 64 years of age category, 97% were very satisfied to satisfied, while 98% of those 65 years of age and older were very satisfied to satisfied. Consumers and proxies were also very satisfied, with proxies being slightly more satisfied than consumers. Ninety-five point eight percent of the consumers were satisfied and 99% of the proxies were satisfied.

# Satisfaction with Caregiver in HCBS Environment – Cultural Needs

Ninety-eight percent of all respondents were very satisfied to satisfied with their caregiver's consideration of their cultural needs. Respondents 65 years of age and older were generally more satisfied (100%) than those respondents age 18 to 64 years (97%). As with the previous questions, both proxies and consumers were satisfied with their caregiver's consideration, however, proxies were slightly more satisfied than consumers. Proxies were 100% satisfied compared to consumers who were 97% satisfied. The findings for this question should be tempered with caution due to the difficulty in understanding this question by consumers and proxies.

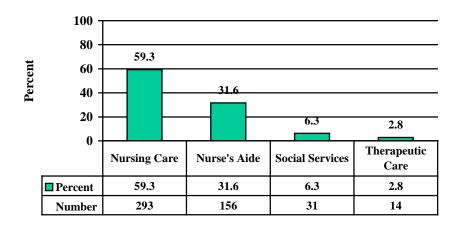
# Satisfaction with the HCBS Caregiver

N	Question	Very		Satisfied		Neutral		Dissatisfied		Very	
0.			sfied	и о						Dissatisfied	
		#	%	#	%	#	%	#	%	#	%
96	Overall										
	Satisfaction	183	64.7	80	28.3	5	1.8	9	3.2	6	2.1
	with										
	HCBS										
	Caregiver										
85	HCBS										
	Caregiver	184	65.0	78	27.6	3	1.1	15	5.3	3	1.1
	Listens										
86	HCBS										
	Caregiver	153	60.7	80	31.8	7	2.8	11	4.4	1	0.4
	Involves										
	Consumer										
	in Decision										
	Making										
87	HCBS										
	Caregiver is	141	51.8	81	29.8	28	10.3	14	5.2	8	2.9
	Reachable										
88	HCBS										
	Caregiver	126	53.2	77	32.5	20	8.4	9	3.8	5	2.1
	Provides										
	Needed										
	Help										
91	HCBS										
	Caregiver	196	69.3	75	26.5	3	1.1	7	2.5	2	0.7
	Respects										
	Consumer										
95	HCBS										
	Caregiver	79	55.6	54	38.0	7	4.9	1	0.7	1	0.7
	Considers										
	Cultural										
	Needs										

#### D. SATISFACTION WITH CAREGIVERS IN THE NURSING FACILITY ENVIRONMENT

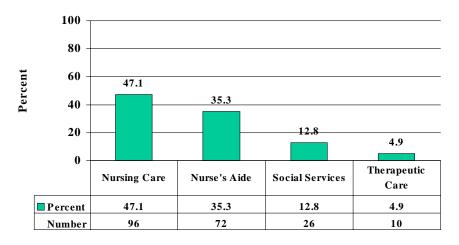
ALTCS consumers who live in a nursing care facility may receive a variety of services to meet their long term care needs. Several members of the health care team, such as nurses, aides, social workers, and therapists may provide these services. In order to respond to questions about nursing facility caregivers, the respondent was first asked to determine which one of these services was most important to them. A list of services provided to consumers in a nursing care facility was read to the respondents. From this list, the respondent was asked to indicate which service was the most important service that the consumer received and then respond to satisfaction questions on that one service. There were a total of 494 respondents. The results are displayed below.

Most Important Services for Consumers in Nursing Facilities Total Respondents = 494



The most important service received was also analyzed based on age and consumer vs. proxy status. As you review the responses below, keep in mind that the respondent was answering these questions based on which service they indicated was the most important one they received. In general, proxies were slightly more satisfied than consumers in all categories. This was also the case for respondents who were 65 years of age and older. They were slightly more satisfied than respondents age 18 to 64. The overall degree of satisfaction of respondents for NF caregivers was slightly less for all questions, than compared with those in HCBS.

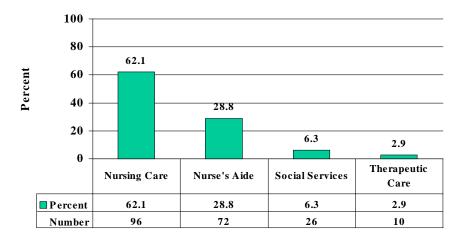
Most Important Services for Consumers in Nursing Facilities, 18 to 64 Years of Age
Total Respondents = 204



Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents.

Most Important Services for Consumers in Nursing Facilities, 65 Years of Age or Older

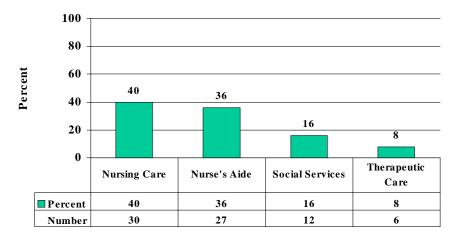
Total Respondents = 351



Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents.

Most Important Services for Consumers in Nursing Facilities, by Consumer Respondent

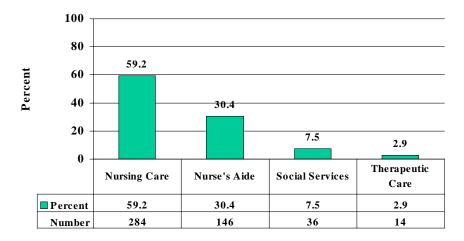
Total Respondents = 75



Note: Not all questions were answered by all respondents.

Most Important Services for Consumers in Nursing Facilities, by Proxy Respondent

Total Respondents = 480



Notes: Percents my not add to 100 due to rounding. Not all questions were answered by all respondents.

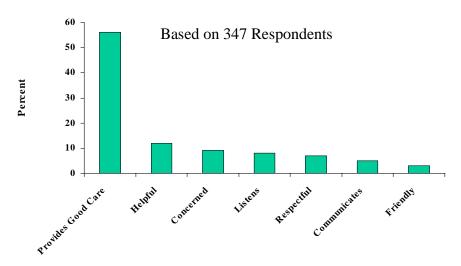
When data is analyzed for all respondents, based on age groups and by consumer vs. proxy status, results show that all categories ranked nursing care as the most important service. Nurse's aide, social service and therapeutic care followed this. These results were not surprising because most individuals living in a nursing facility have a chronic condition requiring nursing care or assistance by a nurse's aide with activities of daily living (bathing, eating, dressing, etc.).

### Satisfaction with Caregiver in Nursing Facility Environment – Overall

Ninety percent of all respondents were very satisfied to satisfied with their nursing facility (NF) caregiver. When results were analyzed according to age groups, 90% of those 18-64 years were very satisfied to satisfied, and 93% of the respondents age 65 and older were very satisfied to satisfied with their NF caregiver. Consumer and proxy responses were analyzed regarding their overall satisfaction with their NF caregiver, and results also indicated a high degree of satisfaction. Consumers were 91% and proxies were 92% very satisfied to satisfied with their caregiver. As was found in the caregiver in HCBS analyses previously discussed, once again consumers aged 18-64 years of age in a NF show a lower rate of satisfaction than those in the higher age category (90% vs. 93%). This, we believe, provides further proof that the younger consumers may want and need different types of services than those 65 years of age and older. It may be advantageous to further investigate the reasons surrounding the lower rate of satisfaction with younger consumers, especially given the fact that these individuals will be increasing in size given the growth of the "Baby Boomer" generation.

To further explore the level of satisfaction with caregivers in the NF environment and to determine what additional characteristics caregivers possess, qualitative data were collected from survey respondents (n=347). Though the total number of qualitative responses was small, the findings were considered with quantitative responses from the phone survey. This provided further support of the caregiver characteristics deemed important to consumers who rely on them for long term care services. Respondents were also asked to indicate reasons for dissatisfaction with caregivers in nursing facilities, again however, the number of responses was too small to generalize from and they were not statistically significant.

# What is Main Reason for Satisfaction with NF Caregivers (Qualitative Question)



Notes: Not all questions were answered by all respondents.

#### Satisfaction with Caregiver in Nursing Facility Environment – Listening

Ninety-one percent of all respondents were very satisfied to satisfied that the NF caregiver listened to their concerns/health care needs. In the two age groups, those 18 to 64 years of age were 88.9% very satisfied to satisfied that their NF caregiver listened to them. Those 65 years of age and older were 92.3% very satisfied to satisfied that their caregiver listened to them. Eightynine point seven percent of the consumers were very satisfied to satisfied that their NF caregiver listened. A slightly larger percentage, 91.8% of the proxies were very satisfied to satisfied that their NF caregiver listened to them. These findings indicate, once again, that caregivers in the NF environment demonstrated good listening skills to their consumers, whether this finding is reported by the consumer or the proxy for the consumer.

## Satisfaction with Caregiver in Nursing Facility Environment – Decision Making Involvement

Eighty-nine point five percent of all respondents were very satisfied to satisfied that their NF caregiver involved the consumer in decision making about their care. Both age groups were equally satisfied with the degree that their caregiver involved them in care. Ages 18-64 years were 86.9% very satisfied to satisfied, and the 65 years and older age group were very satisfied to satisfied 91% of the time. Though consumers and proxies were satisfied with the caregiver involving them in the consumer's care, proxies displayed a higher percentage of satisfaction than

consumers did. Proxies were very satisfied to satisfied 90% compared to 86% for consumers. These findings indicate that the satisfaction rating is high among all groups assessing caregivers in NF who involve consumers.

#### Satisfaction with Caregiver in Nursing Facility Environment - Reachable

Respondents were asked to rate the ease in their ability to reach their NF caregiver if they had a question or concern about their health care status. Eighty-nine percent found it very easy to easy to reach their caregiver. Eighty-five percent of respondents who were 18 to 64 years of age found it very easy to easy to reach their caregiver, while 91% of those respondents 65 years and older found it very easy to easy to reach their caregiver. Proxies rated their ease in reaching their NF caregiver consistently higher than consumers. Ninety-one point nine percent of the proxies rated their ability to reach the NF caregiver as very easy to easy, while 67% of the consumers rated their ability to reach the NF caregiver as very easy to easy. Although most of the consumers rated the "reachable" skill highly for NF caregivers, it is troublesome that consumers in the nursing facility gave a rating of only 67%. This finding should be examined in the NFs to determine what issues make it difficult for a consumer to reach a caregiver.

# Satisfaction with Caregiver in Nursing Facility Environment – Provides Needed Help

Overall respondents were 93% very satisfied to satisfied that their NF caregiver provided them with the help they needed. Ninety-one percent of those 18 to 64 years of age were very satisfied to satisfied that their caregiver provided them with needed help, and 94% of those 65 years of age and older were very satisfied to satisfied. Again, proxies were slightly more satisfied (92%) than consumers (93%). This finding illustrates a high satisfaction rating with caregivers who provide help in NFs.

#### Satisfaction with Caregiver in Nursing Facility Environment – Shows Respect

Over all, 95% of the respondents were very satisfied to satisfied with the respect their NF caregiver showed them. Both age groups were also very satisfied with the respect their NF caregiver showed them. In the 18 to 64 years of age category, 93% were very satisfied to satisfied, while 96% of those 65 years of age and older were very satisfied to satisfied. Consumers and proxies were also satisfied with the respect they were shown by the NF caregiver, with proxies being more satisfied than consumers. Eighty-nine percent of the consumers were satisfied, and 95% of the proxies were satisfied. Again, consumers and proxies rate this skill highly, indicating that caregivers know the importance of respecting their consumers.

### Satisfaction with Caregiver in Nursing Facility Environment – Cultural Needs

Over all respondents were 92% were very satisfied to satisfied with their caregiver's consideration of their cultural needs. Respondents 65 years of age and older were slightly more satisfied (92%) than those respondents age 18 to 64 years (90%). As with the previous questions, both proxies and consumers were satisfied with their caregiver's consideration; however, proxies were more satisfied than consumers. Proxies were 92% satisfied compared to

consumers who were 88% satisfied. The findings for this question should be tempered with caution due to the difficulty in understanding this question by consumers and proxies. The following Table summarizes the data discussed above.

Satisfaction with the NF Caregiver

No.			•	•		Neutral		Dissatisfied		Very	
		Satisfied								Dissatisfied	
		#	%	#	%	#	%	#	%	#	%
120	Overall Satisfaction with NF Caregiver	251	45.9	239	43.7	10	1.8	39	7.1	8	1.5
102	NF Caregiver Listens	243	44.4	248	45.3	7	1.3	36	6.6	13	2.4
103	NF Caregiver Involves Consumer in Decision Making	211	41.2	242	47.3	5	1.0	41	8.0	13	2.5
104	NF Caregiver Is Reachable	242	45.6	221	41.6	8	1.5	40	7.5	20	3.8
105	NF Caregiver Provides Needed Help	208	39.7	276	52.7	2	0.4	32	6.1	6	1.2
111	NF Caregiver Respects Consumer	264	48.1	248	45.2	7	1.3	24	4.4	6	1.1

# E. COMPLAINT PROCEDURES

Early on in the survey development process, it was determined by the Research Team that measuring consumers' knowledge about how and where to file a complaint was an important step to assessing satisfaction with ALTCS. To achieve this goal, a series of questions were asked of survey respondents pertaining to the complaint procedures within AHCCCS.

Results showed that nearly 48% of survey respondents knew who to contact at Maricopa Long Term Care System (MLTCS) to make a complaint. Twenty-six percent of survey respondents had filed a complaint with MLTCS, and of those who filed a complaint, 99.2% indicated that they were very satisfied or satisfied that the complaint was handled fairly. There were no differences between age or placement groupings on the complaint questions. Greater than 48% of the consumers completing this survey did know how to contact Maricopa Long Term Care System to make a complaint after contacting their case manager.

#### F. HEALTH PLAN CHOICES

Several weeks prior to the implementation of this survey, information was mailed to current ALTCS consumers regarding a first-time opportunity to choose among health plans for their medical coverage. If consumers selected a new health plan for their long term medical care, the effective date for their new coverage would be October 1, 2000. Several questions were asked of survey respondents so the Research Team could determine whether or not offering choice among health plans was important to ALTCS consumers.

Results of the data indicated that among all survey respondents, 67% indicated that they had received information regarding the selection of three heath plans in LTC. Consumers are interested in what the various health plans have to offer given that 83% of survey respondents who had received materials indicated that they had read the information regarding the selection of three health plans in LTC. Nearly 50% of those who had taken the time to read the health care information also wanted to have more health plans offered to them.

It is also interesting that those in the younger age category and men were more likely to want more health plan choices. It is not surprising that the younger age category wants more choice as this age category embraces the "Baby Boomers" and it is believed that "Baby Boomers" are more likely to want more in the way of future health care services than do the current population. There were no differences between client and proxies regarding the selection of health plans, nor were there any differences between placement grouping regarding the selection of health plans.

# VIII. CONCLUSION

The results of the Long Term Care Consumer Satisfaction Survey were compiled into four policy issues to guide state leaders as they reform the long term care system in general and improve ALTCS in particular. In late 2001, the research team will re-interview the initial respondents by telephone with the same survey tool. Data will be compared to the current consumer survey, which will function as the base line tool. At that time, a comparison report of the new findings will be shared with the community.

# Four Policy Issues

#### A. HOW CAN AHCCCS PROMOTE THE BROADER CHOICES OF ALTCS SERVICES?

It is clear from the survey that consumers are more satisfied with home and community-based care than with nursing facilities, although satisfaction in both settings is high. Consumers also want to participate more closely in directing their care.

### Policy issue:

The state has the opportunity to:

- Tell consumers and family members that "long term care" no longer means the only option is a nursing facility;
- Re-evaluate how money is allocated for long term care to encourage more home and community-based services;
- Give providers more information about choices and consumer needs; and
- Redefine which home and community-based settings and services can be offered to both the member and the caregiver.

#### B. DO CONSUMERS REALLY WANT TO CHOOSE THEIR HEALTH PLAN?

For the first time, AHCCCS is offering ALTCS members a choice of managed care organizations to serve them, starting with Maricopa County in 2000 and the rest of the state in 2001. The project's survey of ALTCS members came about largely because of this opportunity to choose. Survey respondents underscored this change by emphasizing they wanted to choose who served them.

### Policy issue:

• These surveys are giving the state the chance to see why people choose a health care plan, and why this choice is important to them. A future survey and report will give better direction to establish the best benchmarks for improving care.

# C. HOW CAN CONSUMERS AND PROXIES CONTINUE TO GIVE THEIR VALUABLE INPUT?

There is no question that input from ALTCS consumers is important to help identify which public policy issues should be tackled first

#### Policy issue:

To continue receiving consumer input, state policy makers should:

- Develop a survey center that can be used by long term care contractors, health plans and state agencies that deal with long term care and aging services;
- Share the cost of operating this center among long term care contractors, health plans and state agencies;
- Standardize the way surveys are worded and conducted so there is comparable feedback; and (4) develop a strategic plan to address issues gleaned from continuing input.

#### D. HOW DID THE MARICOPA COUNTY LONG TERM CARE PLAN RATE?

Overall, very well. Consumers were either satisfied or very satisfied with their doctors, case managers and caregivers in either home and community-based settings or nursing facilities. However, the ease with which doctors, caregivers or case managers could be reached received lower ratings.

# Policy issue:

- Show doctors, caregivers and case managers how they can be more available.
- Help doctors become more involved in the consumer's long term care services. Specifically, doctors should include the consumer or proxy in more decision-making, listen more, be more accessible, be more respectful and provide more help.

#### **IN SUMMARY**

This project also has helped assess the level of consumer satisfaction with ALTCS services – overall it is high and the system is working well, but there is much left to do. Finally, this project has helped determine whether choice among consumers is an important consideration. It is, but we need a better understanding of why individuals want this choice.

All participants in this research clearly want a comprehensive approach to deal with an increasing demand on long term care services In Arizona. It has been the intent of this project's working group to help this come about by defining the issues and proposing viable options for policy makers.

### **APPENDIX A**

# **National Advisory Panel Members**

Member Name: Jon A. Christianson, PhD

Professional Title: James A. Hamilton Chair in Health Policy & Management

**Organization:** Department of Healthcare Management

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Jon B. Christainson is an economist with extensive research and teaching experience in the financing and delivery of medical care. He has published in the areas of managed care, rural health care, mental health care, and care process improvement and has collaborated with health care providers in a variety of practice settings to evaluate new treatment approaches. He received his PhD degree from the University of Wisconsin-Madison and currently is on the faculty of the Carlson School of Management at the University of Minnesota where he is the James A. Hamilton Chair in Health Policy Management. Dr. Christianson serves on a number of different editorial boards and scientific advisory panels, and directs the Center for the Study of Healthcare Management in the Department of Healthcare Management at the Carlson School.

Member Name: Dr. Anna Fuentevilla

**Professional Title:** Clinical Assistant Professor of Medicine

**Organization:** University of Arizona, Center on Aging

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Member Name: Julia Huddelston

Professional Title: Manager, Rate Setting, Audits & Waivers

**Organization:** Oregon Department of Human Services

Senior and Disabled Services Division, Research and Finance

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Julia Huddelston manages the Oregon Senior and Disabled Services Division (SDSD) Rate Setting and Audit Unit in the Research and Finance Section. Unit responsibilities include long term care rate setting in both nursing facilities and community based care, cost analysis, reimbursement related rulemaking and both 1915 (c) and 1115 waiver programs. Ms. Huddleston has been employed by SDSD since 1996. She also has extensive experience with employee benefits and provided administrative and actuarial consulting services for more than 15 years.

# **National Advisory Panel Members**

Member Name: Gary R. Ilminen, RN

**Professional Title:** Nurse Consultant

State of Wisconsin Department of Health & Family Services

**Organization:** Division of Health Care Financing, Bureau of Managed Health Care Programs

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A registered nurse since 1987, Mr. Ilminen has worked in long term care or managed care for 12 years. He has contributed to the Wisconsin Long Term Care/Managed Care Initiative and to quality improvement efforts in the State's PACE and Partnership programs. He consults on development and implementation of clinical and performance measures for the Medicaid/Badger Care HMO program. Mr. Ilminen is the author of the book, *Consumer Guide to Long Term Care*.

Member Name: Alfred W. Kaszinak, PhD

Professional Title: Professor of Psychology, Neurology & Psychiatry

**Organization:** University of Arizona

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1503 E. University, Tucson, AZ 85721

Dr. Kaszniak received his PhD degree in clinical and developmental psychology from the University of Illinois in 1976, and completed an internship in clinical neuropsychology at Rush-Presbyterian-St. Luke's Medical Center in Chicago. He is currently Associate Head of Psychology, Director of the Center for Consciousness Studies, and a Professor in the departments of Psychology, Psychiatry, and Neurology. His research focuses primarily on neuropsychological aspects of aging and age-related disorders of the central nervous system, particularly Alzheimer's and Parkinson's diseases, including the evaluation of long term care innovations for older adults with dementing illnesses. Dr. Kaszinak has served on the editorial board of several journals in neuropsychology and gerontological psychology, has been an advisor to several national institutes and agencies concerned with aging and Alzheimer's disease, and is a past-President of the Section on Clinical Gerontology of the American Psychological Association.

# **National Advisory Panel Members**

Member Name: LaRhae Grindal Knatterud

**Professional Title:** Planning Director, Aging Initiative

**Organization:** Minnesota Department of Human Services

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LaRhae Knatterud has a BA in music from Augsburg College in Minneapolis and an MAPA from the Humphrey Institute of Public Affairs at the University of Minnesota where her major filed of study was gerontology and health care policy. From 1972 and 1994 she worked in a number of positions at the Metropolitan Council of the Twin Cities Area in the Aging Program (the Metropolitan Area Agency on Aging). Since 1994, she has worked for the Minnesota Department of Human Services as the planning coordinator for the Minnesota Board on Aging and, most recently, as the Planning Director for the department's Aging Initiative. One of her major responsibilities is the management of Project 2030, a state project that is identifying the impacts of aging of Minnesota's population and preparing the state's response to demographic changes. She has completed over 250 presentations on the project to various groups and organizations, and the project has produced over 20 different publications related to 2030 issues. She is currently leading a team working with the long term care task force comprised of legislators and state agency commissioners to prepare recommendations for reshaping state policies and payment systems to address issues in the long term care system.

Member Name: Pamela J. Parker, Director of the Minnesota Department of Human Services

Professional Title: Director, Integrated Purchasing Demonstrations, Minnesota Department of

**Human Services** 

**Organization:** Minnesota Department of Human Services

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Directs the Minnesota Senior Health Options demonstration which integrates Medicaid and Medicare and acute and long term care financing and service delivery with the support of the Robert Wood Johnson Foundation. Also directs the Minnesota Disability Health Options demonstration and the Demonstration Project for People With Disabilities. Current member of HCFA LTC TAG, NASMD LTC Workgroup, NASHP LTC Committee, former Director of Long Term Care at DHS and first MN State LTC Ombudsman. MPA from Harvard Kennedy School of Government as a Bush Leadership Fellow 1982/83, Governor's Public Service Award for Excellence 1988, Dutch Kastenbaum Outstanding Gerontologist of the Year 1999.

# **APPENDIX B**

QUESTIONNAIRE FILE: p0298.run CREATED: Thur Aug 10 17:33:35 2000

Q1. I am calling because AHCCCS would like to find out what you think about the services 999f|0|you get|1|{999a} gets} from the Arizona Long Term Care System (ALTCS). We want to learn from you and other AHCCCS members so that we can improve our services. We'd appreciate your time to help us.

{999f|1|Do you know enough about {999a}'s }
{999f|1|long term care to answer some questions about it?}

Type h for help on survey

- 0. CLIENT/NAME IN CALLBOX (Skip to Q1a)
- 1. PROXY FAMILY/FRIEND/OTHER ENTER NEXT SCREEN

# ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION

Q 1A. [INTW: IF NECESSARY, ASK:] and what is your relationship to {999a}?

Are you a relative, a friend, or what?

- 1. Proxy family/relative
- 2. Proxy friend
- 3. Other (enter at \$ prompt)
- 9. DK/REF

# ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION

Q1a. This interview will last between 15 to 20 minutes depending upon your answers. Before we begin, we want you to know that your participation is voluntary and your answers are confidential.

No information is ever released that would allow anyone, including AHCCCS, ALTCS or MLTCS to identify you or anyone else in your family. If you decide you don't want to answer any questions, it will not affect {999f|\*} AHCCCS services or benefits in any way. We would really like your opinion because you and other members know first hand how the program is working. This call may be monitored for quality purposes.

Q1b. Skip 1c if not talking to proxy (Skip to Q2)

# Q1c. GENDER OF ALTCS CLIENT?

IF YOU CAN'T TELL ASK: And is {999a} male or female?

- 1. MALE
- 2. FEMALE

# ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION

Q5. First, we would like to ask you about {999f|0|your own|1|{999a}'s} health.

In general, would you say {999f|0|your}{999j|1|his|2|her} health is excellent, very good, good, fair or poor?

- 1. Excellent
- 2. Very good
- 3. Good
- 4. Fair
- 5. Poor
- 9. REF

### ADAPTED FROM: SF-12 QUESTION (PATIENT SATISFACTION QUESTIONNAIRE)

Q6. Compared to one year ago, how would you rate {999f|\*} health in general now?

Would you say {999f|\*} health is much better now than one year ago, somewhat better now than one year ago, about the same as one year ago, somewhat worse now than one year ago, or much worse now than one year ago?

- 1. Much Better
- 2. Somewhat Better
- 3. About the Same
- 4. Somewhat Worse
- 5. Much Worse
- 9. REF

# ADAPTED FROM: SF-12 QUESTION (PATIENT SATISFACTION QUESTIONNAIRE)

- Q9. {999f|\*} currently living at home, in a facility such as Assisted Living, Adult Foster Care, or a Nursing Home.
  - 1. Yes, Home
  - 2. Yes, Assisted Living
  - 3. Yes, Adult Foster Care
  - 4. Yes, Nursing Home
  - 9. DK/REF

# ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION

Q10. The next questions ask about the services provided to {999f|\*} by {999f|0|your}{999j|1|his|2|her} case manager and how satisfied you are with these services.

Do you know who {999f|0|your|1|{999a}'s} case manager is?

[CLARIFICATION: The case manager is the person who reviews your needs and assists with arranging for services such as Home Delivered Meals, Nursing Services, Housekeeping, Attendant Care, Adult Foster Care, Assisted Living, and Nursing Home Care.]

- 1. YES
- 2. NO (Skip to Q50)
- 9. DK/REF (Skip to Q50)

# ADAPTED FROM: CAHPS (2.0H AND THE NON-MEDICAL HOME AND COMMUNITY- BASED SERVICES CUSTOMER SATISFACTION SURVEY 1999.

Q12. How satisfied are you that the case manager listens to you?

Are you Very Satisfied, Satisfied, Dissatisfied or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY, THE NON-MEDICAL HOME AND COMMUNITY-BASED SERVICES CUSTOMER SATISFACTION SURVEY OF 1999, AND CAHPS( 2.0H.)

Q20. How satisfied are you that the case manager involves you when making decisions about {999f|0|your}{999j|1|his|2|her} care?

Would you say? Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY, AND THE NON-MEDICAL HOME AND COMMUNITY-BASED SERVICES CUSTOMER SATISFACTION SURVEY OF 1999.

- Q21. Have you tried to reach {999f|\*} case manager in the last 12 months?
  - 1. YES
  - 2. N0 (Skip to Q26a)
  - 9. DK/REF (Skip to Q26a)

# ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q25. How easy is it for you to reach {999f|\*} case manager?

Would you say it is Very Easy, Easy, Hard, or Very Hard?

- 1. Very Easy
- 2. Easy
- 3. Hard
- 4. Very Hard
- 8. Neutral/Neither
- 9. DK/REF

**ADAPTED FROM: CAHPS(2.0H.)** 

Q26. When you call {999f|\*} case manager, how satisfied are you that {999f|0|you get}{999j|1|he gets|2|she gets} the help {999f|0|you need}{999j|1|he needs|2|she needs}.

Are you Very Satisfied, Satisfied, Dissatisfied or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

#### **ADAPTED FROM: CAHPS (2.0H.)**

Q26a. DO NOT READ

IWVR: THIS IS THE PLACE TO QUIT IF RESPONDENT HAD DIFFICULTIES UNDERSTANDING AND ANSWERING PRIOR QUESTIONS

- 1. CONTINUE, R DOING OK, OR PROXY COMES TO PHONE
- 2. QUIT, R NOT ABLE TO GIVE ACCURATE ANSWERS (Skip to Q260)
- Q 27. How satisfied are you with the respect {999f|\*} case manager shows you?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY, AND THE NON-MEDICAL HOME AND COMMUNITY-BASED SERVICES CUSTOMER SATISFACTION SURVEY OF 1999.

Q30. If {999f|\*} needed some other service that {999f|0|you are not}{999j|1|he is not|2|she is not} currently receiving to maintain independence what would it be?

[CLARIFICATION on "INDEPENDENCE": Doing more on your own.]

Q40. If {999f|\*} special cultural needs such as food or religious beliefs, how satisfied are you that the case manager takes them into consideration?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied or does this not apply to you?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 5. Does Not Apply
- 8. Neither/Neutral
- 9. DK/REF

# ADAPTED FROM: PART AHCCCS ACUTE CARE SURVEY AND ORIGINAL AHCCCS/HSAG QUESTION.

Q41. Overall, how satisfied are you with the case manager now?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied (Skip to Q46)
- 4. Very Dissatisfied (Skip to Q46)
- 8. Neither/Neutral (Skip to Q50)
- 9. DK/REF (Skip to Q50)

### **ADAPTED FROM: CAHPS(2.0H.)**

Q42. What is the main reason you are satisfied with the case manager?

[IVWR: PLEASE BE PATIENT; LET THEM ANSWER] [BUT IF R HAS NO IDEA, ENTER 9]

\$. (Skip to Q50) 9.

ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEMS LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q43. These are some of the reasons you may be satisfied with the case manager. Because he or she listens to you, involves you in planning services, treats you with respect, is your advocate when necessary, is accessible, helps you retain your independence, considers race, beliefs and custom, or the quality of services received is good.

Are any of these the main reason you are satisfied with your case manager?

- 1. Listens (Skip to Q50)
- 2. Involves in Planning (Skip to Q50)
- 3. Respects you (Skip to Q50)
- 4. Advocate (Skip to Q50)
- 5. Accessible (Skip to Q50)
- 6. Retain Independence (Skip to Q50)
- 7. Considers Culture (Skip to Q50)
- 8. Good Services (Skip to Q50)
- 9. DK/REF (Skip to Q50)

# ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEMS LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q 46. What is the main reason you are dissatisfied with your case manager?

[IVWR: PLEASE BE PATIENT; LET THEM ANSWER] [BUT IF R HAS NO IDEA, ENTER 9] \$. (Skip to Q50) 9.

ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEMS LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q47. These are some of the reasons you may be dissatisfied with the case manager. Because he or she doesn't listen to you, doesn't involve you in planning services, does not treat you with respect, is not your advocate when necessary, is not accessible, does not help you retain your independence, doesn't consider race, beliefs and custom, the quality of services received is not good, or something else.

Are any of these the main reason you are dissatisfied with your case manager?

- 1. Does not Listen
- 2. Does not Involve in Planning
- 3. Does not Respect You
- 4. Does not Advocate
- 5. Isn't Accessible
- 6. Does not Retain Independence
- 7. Does not Consider Culture
- 8. Bad Services
- 9. DK/REF

# ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEMS LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q50. The next questions ask about the services provided to  $\{999f|0|you|1|\{999a\}\}$  by  $\{999f|0|your\}\{999j|1|his|2|her\}$  doctor.

We are interested in knowing how satisfied you are with the care provided by {999f|\*} doctor.

Do you have one person you think of as {999f|\*} doctor?

- 1. YES
- 2. NO (Skip to Q80)
- 9. DK/REF (Skip to Q80)

# ADAPTED FROM: CAHPS (2.0H) AND THE NON-MEDICAL HOME AND COMMUNITY-BASED SERVICES CUSTOMER SATISFACTION SURVEY 1999.

Q55. How satisfied are you that the doctor listens to you?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY, THE NON-MEDICAL HOME AND COMMUNITY-BASED SERVICES CUSTOMER SATISFACTION SURVEY OF 1999, AND CAHPS( 2.0H.

Q60. How satisfied are you that {999f|\*} doctor involves you when making decisions about {999f|0|your}{999j|1|his|2|her} care?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY, AND THE NON-MEDICAL HOME AND COMMUNITY-BASED SERVICES CUSTOMER SATISFACTION SURVEY OF 1999.

Q67. When you call {999f|\*} doctor, how easy is it for you to reach someone who can help you?

Would you say it is very easy, easy, hard, or very hard?

[CLARIFICATION: SOMEONE WHO CAN ANSWER YOUR QUESTIONS]

- 1. Very Easy
- 2. Easy
- 3. Hard
- 4. Very Hard
- 8. Neutral/Neither
- 9. DK/REF

# ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q68. When you call {999f|\*} doctor, how satisfied are you that {999f|0|you get|1|{999a} gets} the help {999f|0|you need}{999j|1|he needs|2|she needs}?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

## **ADAPTED FROM: CAHPS(2.0H.)**

Q70. How satisfied are you with the respect shown by {999f|\*} doctor for what you have to say?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY, AND THE NON-MEDICAL HOME AND COMMUNITY-BASED SERVICES CUSTOMER SATISFACTION SURVEY OF 1999.

Q72. If {999f|\*} special cultural needs such as food or religious beliefs, how satisfied are you that the doctor takes them into consideration?

Would you say you are Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied or Does this not apply to you?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 5. Does not Apply
- 8. Neither/Neutral
- 9. DK/REF

# ADAPTED FROM: PART AHCCCS ACUTE CARE SURVEY AND ORIGINAL AHCCCS/HSAG QUESTION.

Q73. Overall, how satisfied are you with {999f|\*} doctor now?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied (Skip to Q75)
- 4. Very Dissatisfied (Skip to Q75)
- 8. Neither/Neutral (Skip to Q77)
- 9. DK/REF (Skip to Q77)

# ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q74. What is the main reason you are satisfied with your doctor?

[IVWR: PLEASE BE PATIENT; LET THEM ANSWER] [BUT IF R HAS NO IDEA, ENTER 9]

\$. (Skip to Q77) 9.

# ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q74a. These are some of the reasons you may be satisfied with the doctor. Because he or she listens to you, involves you in planning services, treats you with respect, is your advocate when necessary, is accessible, helps you retain your independence, considers race, beliefs and custom, or the quality of services received is good.

Are any of these the main reason you are satisfied with your doctor?

- 1. Listens (Skip to Q77)
- 2. Involves in Planning (Skip to Q77)
- 3. Respects You (Skip to Q77)
- 4. Advocate (Skip to Q77)
- 5. Accessible (Skip to Q77)
- 6. Retain Independence (Skip to Q77)
- 7. Considers Culture (Skip to Q77)
- 8. Good Services (Skip to Q77)
- 9. DK/REF (Skip to Q77)

# ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q75. What is the main reason you are dissatisfied with your doctor?

[IVWR: PLEASE BE PATIENT; LET THEM ANSWER] [BUT IF R HAS NO IDEA, ENTER 9]

\$. (Skip to Q77) 9.

ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q75a. These are some of the reasons you may be dissatisfied with the doctor. Because he or she doesn't listen to you, doesn't involve you in planning services, does not treat you with respect, is not your advocate when necessary, is not accessible, does not help you retain your independence, doesn't consider race, beliefs and custom, the quality of services received is not good, or something else.

Are any of these the main reason you are dissatisfied with your doctor?

- 1. Does not Listen
- 2. Does not Involve in Planning
- 3. Does not Respect You
- 4. Does not Advocate
- 5. Isn't Accessible
- 6. Does not Retain Independence
- 7. Does not Consider Culture
- 8. Bad Services
- 9. DK/REF

# ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q77. We know there are many different types of insurance plans that pay for doctor visits.

Does AHCCCS pay for {999f|\*} doctor's visits?

[IVWR: MAY KNOW AS: Maricopa County Long Term Care, or Long Term Care AHCCCS or ALTCS]

- 1. YES (Skip to Q80)
- 2. NO
- 9. DK/REF (Skip to Q80)

## ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q79. Why did you choose that doctor rather than a doctor with MLTCS, AHCCCS, ALTCS or LTC?

h = help on MLTCS, AHCCCS

h. (Skip to Q9951)

ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

#### Q80. Check answer to Q9

- 1. If home based, continue, else
- 2. Assisted living: go to facility based section (Skip to Q100)
- 3. Adult foster care: go to facility based section (Skip to Q100)
- 4. Nursing home: go to facility based section (Skip to Q100)
- Q82. The next questions ask about the services {999f|\*} at home. We are interested in knowing how satisfied you are with the in-home services provided to {999f|0|you|1|{999a}}.

I am going to read a list of services available to {999f|0|you|1|{999a}} in a home setting. Please tell me which is the most important service {999f|0|you receive}{999j|1|he receives|2|she receives}.

- 1. Attendant Care
- 2. Housekeeping
- 3. Personal Care Aide
- 4. Home Delivered Meals
- 5. Nursing Care
- 6. Home Health Aide
- 7. Proxy is caregiver (SKIP CAREGIVER QUESTIONS) (Skip to Q 99)
- 8. Doesn't get any Services at Home (Skip to Q 99)
- 9. DK/REF (Skip to Q 99)

### ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q85. The next few questions are about the services  $\{999f|0|\text{you receive}|1|\{999a\} \text{ receives}\}\$  from the  $\{82|*\}$ .

Overall, how satisfied are you with how the  $\{82|*\}$  listens to you?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q86. Overall, how satisfied are you that {999f|0|your|1|{999a}'s} {82|\*} involves you when making decisions about {999f|0|your|1|{999a}'s} care?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY, AND THE NON-MEDICAL HOME AND COMMUNITY-BASED SERVICES CUSTOMER SATISFACTION SURVEY OF 1999.

Q87. How easy is it for you to reach {999f|0|your|1|{999a}'s} {82|\*}?

Would you say it is Very Easy, Easy, Hard, or Very Hard?

- 1. Very Easy
- 2. Easy
- 3. Hard
- 4. Very Hard
- 8. Neutral/Neither
- 9. DK/REF

### **ADAPTED FROM: CAHPS(2.0H.)**

Q88. When you call  $\{999f|0|your|1|\{999a\}'s\}$   $\{82|*\}$ , how satisfied are you that  $\{999f|0|you get|1|\{999a\}gets\}$  the help  $\{999f|0|you need\}\{999j|1|he needs|2|she needs\}$ ?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

**ADAPTED FROM: CAHPS( 2.0H.)** 

Q91. How satisfied are you with the respect shown by {999f|0|your|1|{999a}'s} {82|\*} for what you have to say?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

## ADAPTED FROM: 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q95. If {999f|0|you have|1|{999a} has} special cultural needs such as food or religious beliefs, how satisfied are you that the {82|\*} takes them into consideration?

Would you say you are Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied or Does this not apply to you?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 5. Does not Apply
- 8. Neither/Neutral
- 9. DK/REF

## ADAPTED FROM: PART FROM AHCCCS ACUTE CARE SURVEY AND ORIGINAL AHCCCS/HSAG QUESTION.

Q96. Overall, how satisfied are you with {999f|0|your|1|{999a}'s} {82|\*} now?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied (Skip to Q98)
- 4. Very Dissatisfied (Skip to Q98)
- 8. Neither/Neutral (Skip to Q99)
- 9. DK/REF (Skip to Q99)

### **ADAPTED FROM: CAHPS(2.0H.)**

Q97. What is the main reason you are satisfied with {999f|0|your|1|{999a}'s} {82|\*}?

[IVWR: PLEASE BE PATIENT; LET THEM ANSWER] [BUT IF R HAS NO IDEA, ENTER 9]

\$. (Skip to Q99) 9.

## ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q97a. These are some of the reasons you may be satisfied with the {82|\*}. Because he or she listens to you, involves you in planning services, treats you with respect, is your advocate when necessary, is accessible, helps you retain your independence, considers race, beliefs and custom, or the quality of services received is good.

Are any of these the main reason you are satisfied with your  $\{82|*\}$ ?

- 1. Listens (Skip to Q99)
- 2. Involves in Planning (Skip to Q99)
- 3. Respects You (Skip to Q99)
- 4. Advocate (Skip to Q99)
- 5. Accessible (Skip to Q99)
- 6. Retain Independence (Skip to Q99)
- 7. Considers Culture (Skip to Q99)
- 8. Good Services (Skip to O99)
- 9. DK/REF (Skip to Q99)

## ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q98. What is the main reason you are dissatisfied with {999f|0|your|1|{999a}'s} {82|\*}?

[IVWR: PLEASE BE PATIENT; LET THEM ANSWER] [BUT IF R HAS NO IDEA, ENTER 9]

\$. (Skip to Q99) 9.

ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY. Q98a. These are some of the reasons you may be dissatisfied with the {82|\*}. Because he or she doesn't listen to you, doesn't involve you in planning services, does not treat you with respect, is not your advocate when necessary, is not accessible, does not help you retain your independence, doesn't consider race, beliefs and custom, the quality of services received is not good, or something else.

Are any of these the main reason you are dissatisfied with your  $\{82|*\}$ ?

- 1. Does not Listen
- 2. Does not Involve in Planning
- 3. Does not Respect You
- 4. Does not Advocate
- 5. Isn't Accessible
- 6. Does not Retain Independence
- 7. Does not Consider Culture
- 8. Bad Services
- 9. DK/REF

## ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q99. Why did {999f|0|you|1|{999a}} choose to live at home?

\$. (Skip to Q130) --END OF HOME SECTION

### ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

#### Q100. BEGINNING OF FACILITY SECTION

The next few questions ask you about the services provided by

(Facility Type Given In Q9).

I am going to read a list of services available to {999f|0|you|1|{999a}}. Please tell me which is the most important service {999f|0|you receive}{999j|1|he receives|2|she receives}.

- 1. Nurses Aide [AKA "CNA" Certified Nurse Assistant"]
- 2. Nursing Care
- 3. Therapeutic Care
- 4. Social Services
- 9. DK/REF (Skip to Q127)

### ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q102. Overall, how satisfied are you that the  $\{100|*\}$  listens to you?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY, THE NON-MEDICAL HOME AND COMMUNITY-BASED SERVICES CUSTOMER SATISFACTION SURVEY OF 1999, AND CAHPS(2.0H.)

Q103. Overall, how satisfied are you that {999f|0|your|1|{999a}'s} {100|\*} involves you when making decisions about {999f|0|your|1|{999a}'s} care?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY, THE NON-MEDICAL HOME AND COMMUNITY-BASED SERVICES CUSTOMER SATISFACTION SURVEY OF 1999.

Q104. How easy is it to reach the  $\{100|*\}$  when you need him or her?

Would you say it is Very Easy, Easy, Hard, or Very Hard?

- 1. Very Easy
- 2. Easy
- 3. Hard
- 4. Very Hard
- 8. Neutral/Neither
- 9. DK/REF

**ADAPTED FROM: (CAHPS(2.0H.)** 

Q105. How satisfied are you that when you contact the {100|\*}, you get the help you need?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

## ADAPTED FROM: CAHPS(2.0H.)

Q111. How satisfied are you with the respect shown by the  $\{100|*\}$  for what you have to say?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 8. Neither/Neutral
- 9. DK/REF

## ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q116. If {999f|0|you have|1|{999a} has} special cultural needs such as food or religious beliefs, how satisfied are you that the {100|\*} takes them into consideration?

Would you say you are Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied or Does this not apply to you?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied
- 4. Very Dissatisfied
- 5. Does not Apply
- 8. Neither/Neutral
- 9. DK/REF

ADAPTED FROM: PART AHCCCS ACUTE CARE SURVEY AND ORIGINAL AHCCCS/HSAG QUESTION.

Q120. Overall, how satisfied are you with the  $\{100|*\}$  now?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

- 1. Very Satisfied
- 2. Satisfied
- 3. Dissatisfied (Skip to Q 126)
- 4. Very Dissatisfied (Skip to Q 126)
- 8. Neither/Neutral (Skip to Q 127)
- 9. DK/REF (Skip to Q 127)

### **ADAPTED FROM: CAHPS(2.0H.)**

Q125. What is the main reason you are satisfied with the  $\{100|*\}$ ?

[IVWR: PLEASE BE PATIENT; LET THEM ANSWER] [BUT IF R HAS NO IDEA, ENTER 9]

- \$. (Skip to Q127) 9.
- Q125a. These are some of the reasons you may be satisfied with the {100|\*}. Because he or she listens to you, involves you in planning services, treats you with respect, is your advocate when necessary, is accessible, helps you retain your independence, considers race, beliefs and custom, or the quality of services received is good.

Are any of these the main reason you are satisfied with your  $\{100|*\}$ ?

- 1. Listens (Skip to Q127)
- 2. Involves in Planning (Skip to Q127)
- 3. Respects You (Skip to Q127)
- 4. Advocate (Skip to Q127)
- 5. Accessible (Skip to Q127)
- 6. Retain Independence (Skip to Q127)
- 7. Considers Culture (Skip to Q127)
- 8. Good Services (Skip to Q127)
- 9. DK/REF (Skip to Q127)

## ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q126. What is the main reason you are dissatisfied with the  $\{100|*\}$ ?

[IVWR: PLEASE BE PATIENT; LET THEM ANSWER] [BUT IF R HAS NO IDEA, ENTER 9]

\$. (Skip to Q127) 9.

## ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q126a. These are some of the reasons you may be dissatisfied with the {100|\*}. Because he or she doesn't listen to you, doesn't involve you in planning services, does not treat you with respect, is not your advocate when necessary, is not accessible, does not help you retain your independence, doesn't consider race, beliefs and custom, the quality of services received is not good, or something else.

Are any of these the main reason you are dissatisfied with your  $\{100a|*\}$ ?

- 1. Does not Listen
- 2. Does not Involve in Planning
- 3. Does not Respect You
- 4. Does not Advocate
- 5. Isn't Accessible
- 6. Does not Retain Independence
- 7. Does not Consider Culture
- 8. Bad Services
- 9. DK/REF

## ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q127. Did  $\{999f|0|\text{you}|1|\{999a\}\}\$  choose to live in  $\{9|*\}$ ?

- 1. YES
- 2. NO (Skip to Q127C)
- 9. DK/REF (Skip to Q127C)

### ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q127a. Why is that?

[CLARIFICATION: Why did {999f|0|you|1|{999a}} decide to live in {9|\*}

### ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q127c. Now that  $\{999f|0|you live\}\{999j|1|he lives|2|she lives\}$  in  $\{9|*\}$ , what is most important to you?

[IVWR: PLEASE BE PATIENT; LET THEM ANSWER] [BUT IF R HAS NO IDEA, ENTER 9]

\$. (Skip to Q127g) 9.

### ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q127d. ASK 127e FOR HOME; 127f FOR FACILTY

Q127e. Some people have said that they live in  $\{9|*\}$  because it is important to have the freedom to come and go, to have good staff, because they like the environment, enjoy the privacy, it keeps them close to their families, or safety concerns.

Are any of these important to you, or is there some other reason?

- 1. Freedom to Come and Go (Skip to Q127g)
- 2. Have Good Staff (Skip to Q127g)
- 3. Like Environment (Skip to Q127g)
- 4. Enjoy Privacy (Skip to Q127g)
- 5. Keep Close to Family (Skip to Q127g)
- 6. Safety Concerns (Skip to Q127g)
- 7. Other (Enter Answer) (Skip to Q127g)
- 9. DK/REF (Skip to Q127g)

### ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q127f. Some people have said that they live in a nursing facility because it is important to be close their family, to have good staff, because they like the environment, or safety concerns.

Are any of these important to you, or is there some other reason?

- 1. Keep me Close to my Family
- 2. Have Good Staff
- 3. Like Environment
- 4. Safety Concerns
- 5. Other (Enter Answer)
- 9. DK/REF

## ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q127g. Would you recommend  $\{9|*\}$  to others?

- 1. YES
- 2. NO
- 9. DK/REF (Skip to Q130)

## ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q128. Why is that?

## ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q130. The next questions ask about how satisfied you are with the services provided by Maricopa County Long Term Care.

Do you know how to contact Maricopa County Long Term Care to ask a question or to register a complaint or concern about the care or services {999f|\*} receiving?

[IWVR: IF NECESSARY READ: If you have a complaint and shared it with the case manager and it did not get resolved, do you know who to contact next?

- 1. YES
- 2. NO (Skip to Q135)
- 9. DK/REF (Skip to Q135)

## ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q131. Have you ever made a complaint?

- 1. YES
- 2. NO (Skip to Q135)
- 9. DK/REF (Skip to Q135)

## ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q132. Please tell me how satisfied you are with how fairly your complaint or concern was handled?

Would you say you are: Very Satisfied, Satisfied, Dissatisfied, or Very Dissatisfied?

[IWVR: IF MORE THAN ONE IN LAST 12 MONTHS, MOST RECENT COMPLAINT]

- 1. Very Satisfied (Skip to Q135)
- 2. Satisfied (Skip to Q135)
- 3. Dissatisfied (Skip to Q135)
- 4. Very Dissatisfied (Skip to Q135)
- 5. Complaint Has Not Been Settled
- 8. Neither/Neutral (Skip to Q135)
- 9. DK/REF (Skip to Q135)

# ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q133. If your complaint has not been settled, have you been informed about how to get help from AHCCCS?

[IWVR: IF NECESSARY READ: If you have a complaint and shared it with the Maricopa County Long Term Care and it did not get resolved, do you know who to contact next?

- 1. YES
- 2. NO
- 9. DK/REF

## ADAPTED FROM: THE 1999 MARICOPA INTEGRATED HEALTH SYSTEM LONG TERM CARE NURSING HOME CLIENT SURVEY.

Q135. We are also interested in knowing whether or not offering you a choice among health plans is important.

Recently you may have received information from ALTCS about choosing among health plans for your long term care services. For the first time, long term care clients will be able to select among three health plans for their long term care services.

Have you received the information regarding your health plan from ALTCS?

- 1. YES
- 2. NO (Skip to Q135b)
- 9. DK/REF (Skip to Q 135b)

### ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q135a. Have you read it?

- 1. YES
- 2. NO
- 9. DK/REF

ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q135b. ALTCS (Arizona Long Term Care System) provides long term care services, which include in-home services, case management, and medical and nursing home care. Each health plan may work with different long term care providers.

Do you think there should be more health plans to choose from?

Would you say yes or no?

- 1. YES
- 2. NO
- 9. DK/REF (Skip to Q 160)

### ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q135e. Why?

## ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q160. How do you think AHCCCS could improve the long term care program?

[CLARIFICATION for AHCCCS: the State; State government]

h = help on Terms (ALTCS/AHCCCS/ETC)

h. (Skip to Q9951)

## ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q202. We may want to call you back next year to find out how your opinions and experiences may have changed.

Would that be OK with you?

- 1. YES
- 2. NO

### ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q202b. ONLY ASK 203 IF LIVE AT HOME, ELSE: (Skip to Q 205)

#### Q203. (This is our last question.)

Because persons who live alone may have different experiences with long term care than persons who live with someone else in their home, we'd like to ask about {999f|\*} situation.

{999f|0|Do you|1|Does {999a}} live alone, or does someone live with {999f|0|you}{999j|1|him|2|her}?

- 1. Live Alone
- 2. Someone Else Lives With Them (Skip to Q260)
- 9. DK/REF (Skip to Q260)

### ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q205. {999f|0|And do you|1|And does {999a}} have family members or a close friend nearby to assist {999f|0|you}{999j|1|him|2|her}?

- 1. YES (HAS FAMILY/FRIEND CLOSE)
- 2. NO (ALONE)
- 9. DK/REF

### ADAPTED FROM: ORIGINAL AHCCCS/HSAG QUESTION.

Q300. And that concludes our survey. Thank you very much for your cooperation.

FOR QUESTIONS ABOUT SERVICES: you can call your case manager or the Maricopa Long Term Care System office where you are receiving services at 602-344-8700.

FOR ANOTHER BROCHURE: To get another copy of the AHCCCS letter, which outlines the change to multiple health plans, call 602-344-8760

FOR QUESTIONS ABOUT OUR QUESTIONS: If you have questions about this study please call Marilea Rose at Health Services Advisory Group, 602-665-6138.

[PRESS <ENTER> TO CONTINUE

Q400. Rate the respondent's understanding of the questions.

- 1. R Understood all or almost all the questions
- 2. R Had difficulty understanding a couple of questions
- 3. R Had difficulty understanding more than 10 questions
- 4. Had difficulty with a lot of questions

9.

Q401a. Was language a problem?

- 1. YES
- 2. NO

Q401b. Was hearing a problem?

- 1. YES
- 2. NO

Q401c. Is there anything else we need to know about any difficulties the respondent had?

- 1. YES (Skip to Q998c)
- 2. NO (Skip to Q998c)

# Q995k. BEGINNING OF BOUNCE-BACK QUESTION(S) FOR HELP OR REFERENCE [SURVEY PURPOSE AND CONFIDENTIALITY]

We are doing this survey to find out about people opinions of their long term care.

We want to find out your experiences with the care you receive.

We are NOT selling anything - we work for Arizona State University.

You may call my supervisor and ask him any questions, or verify this survey: JoAnne Valdenegro or Bill Edwards, 480-965-5009.

If you want to verify with AHCCCS, please call John Black at 602-344-8700.

You may also call HSAG if you have questions, call Marilea Rose at 602-665-6138. (Health Services Advisory Group).

I had to sign a statement promising to keep secret all the answers I heard, and so did all the other interviewers and my supervisors.

### Q9951. BEGINNING OF BOUNCE-BACK QUESTION(S) FOR HELP OR REFERENCE

AHCCCS is the state (Medicaid) that oversees the long term care program in Arizona. (Arizona Health Care Cost Containment System).

ALTCS is the name of the long term care program at AHCCCS (Arizona Long Term Care System).

MLTCS is paid by AHCCCS to provide long term care services. (Maricopa Long Term Care System).

## **APPENDIX C**

 Table 1.
 Characteristics of Eligible Population vs. Survey Respondents

Eligible Population (n=7,189)	Respondents (n=1,031)
76% Over Age 65	62% Over Age 65
69% Female	65% Female
55% in Nursing Facility	52% in Nursing Facility
45% in HCBS	48% in HCBS
Average Time of Enrollment 3.9 Years	Average Time of Enrollment 3.8 Years

Table 2. Characteristics of Respondents vs. Non-Respondents

Respondents (n=1,031)	Non-Respondents (n=790)
62% Over Age 65	59% Over Age 65
65% Female	64 Female
52% in Nursing Facility	63% in Nursing Facility
48% in HCBS	37% in HCBS
Average time enrollment 3.9 years	Average time enrollment 3.9 years

#### ABOUT THE LTC SURVEY

To learn more about how to strategically plan for the future of our long term care systems in Arizona, the Flinn Foundation funded the first state Medicaid long term care consumer satisfaction survey.

#### **ABOUT THE DATA**

The quantitative data presented in this report was collected from participants of a consumer telephone survey. Individuals who participated were either direct members of the care (consumers) or making decisions for the consumer about their care (proxies).

#### **ABOUT THE EXECUTIVE SUMMARY**

This series, What Current Consumers Say (Survey Book), is funded by a grant from The Flinn Foundation.

This report is the second in a series of six publications. Other documents available are:

- 1. What the Experts Say? (Literature Review)
- 2. Survey Data Book
- 3. Baby Boomers: Who Me? (Focus Groups)
- 4. Final Report: Now and the Next Generation
- 5. Trifold Final Report Summary: Now and the Next Generation







For more information, please contact:

Arizona Health Care Cost Containment System (AHCCCS) 801 E. Jefferson, M/D 4200 Phoenix, Arizona 85034

www.ahcccs.state.az.us







This report has been a joint effort of three organizations.

AHCCCS, HSAG, and Flinn Foundation.

The intent has been to define the issues and propose viable options for policy-makers regarding long term care in Arizona.

Additional copies can be obtained from the AHCCCS website at www.ahcccs state az us.

Long Term Care: Now and the Next Generation:

Final Report
Final Report Summary
Baby Boomers: Who Me?
What the Consumers Say
What the Experts Say
Survey Data Book